Diabetes distress

Diabetes distress (DD) is a psychological state, found in persons with diabetes and their caregivers. This is a state which causes significant emotional distress, however it fails to meet the diagnostic criteria for major depressive disorder (MDD). The 2017 Standards of Medical Care in Diabetes, published by the American Diabetes Association, mentions the need to assess and manage DD to improve self-care and glycemic control and reduce cardiovascular risk and all-cause mortality.[1]

DEFINITION

DD has been defined in various ways. Kreider (2017) refers to DD as an emotional state where people experience feelings such as stress, guilt, or denial that arise from living with diabetes and the burden of self-management.[2] Gonzalez *et al.* (2011) describe DD as the unique, often hidden emotional burdens and worries that are part of the spectrum of patient experience when managing a severe, demanding chronic disease like diabetes.[3] Fisher *et al.* (2012) define DD as significant emotional reactions to the diagnosis, threat of complications, self-management demands, or unsupportive social structures surrounding diabetes.[4] DD, according to Fisher *et al.*, (2012) refers to fears of complications, worries about hypoglycemia and the variety of stresses, strains, and concerns people with diabetes have on a day-to-day basis. Describing the term as such makes it more specific and alive to individuals who live with diabetes. He also highlights the existence of DD in family members who care for persons with diabetes.[5]

We define DD as an emotional response characterized by extreme apprehension, discomfort, or dejection, due to perceived inability to cope with the challenges and demands of living with diabetes. Our definition, mentioned above, draws from the conceptualization of DD as proposed by Fisher. [5,6]

EPIDEMIOLOGY

Community-based studies reveal that DD may occur in up to 45% of persons with type 2 diabetes mellitus. DD is more frequent in younger people, and in insulin-users. Other data suggest that 39% of Type 1 and 35% of Type 2 patients experience significant DD at any given time.[4,6]

ETIOLOGY

DD is part of living with diabetes experience. Self-perception of inadequacy and uncertainty, poor opinion of the accessibility and/or ability of the diabetes care professional, and dissatisfaction with social support are the main factors contributing to the DD [Table 1]. The risk of DD is higher during periods of change, as listed in Table 2.

SYMPTOMATOLOGY AND DIAGNOSIS

The symptoms of DD are similar to those of MDD, but are not severe enough to qualify as MDD. DD can be diagnosed using validated screening and diagnostic tools [Table 3].[2] These instruments differ in the number of items, ease of administration, and utility in different types of diabetes, treatment regimens, or stakeholders. It must be noted that diagnostic and screening tools for DD are different from those for MDD. Some of the core symptoms of DD are listed in Table 4.

Table 1: Etiology of diabetes distress

Physician
Limited access
Perceived inability
Poor communication skills
Person with diabetes
Lack of motivation
Perceived inability to self-manage
Heavy burden of complications
Uncertain outcomes
Friends/family/community
Lack of understanding
Lack of support

Table 2: Precipitating factors of diabetes distress

Change in life
Phase, e.g., adolescence, marriage, pregnancy, menopause
Environment e.g., work, residence
Change in disease state, e.g.,
Glycemic control
Extra glycemic complications
Acute
Chronic
Change in health care
Support, e.g., from family colleagues
System, e.g., HCP team, insurance
Change in disease management
Investigations
Treatment
Nonpharmacological
Pharmacological

HCP: Health care provider

Table 3: Diagnosis of diabetes distress

Scale	Number of domains	Number of items
DSS-17		
Emotional burden subscale	4	17
Physician related distress subscale		
Regimen related distress subscale		
Diabetes related interpersonal distress		
Type 1-DDS		
Powerlessness subscale	7	28
Management distress subscale		
Hypoglycemia distress subscale		
Negative social perceptions subscale		
Eating distress subscale		
Physician distress subscale		
Friend/family distress subscale		
Parent-DDS		
Personal distress subscale	4	20
Teen management distress subscale		
Parent/teen relationship distress subscale		
Healthcare team distress subscale		
Partner-DDS		
My partner's diabetes management	4	21
How best to help		
Diabetes and me		
Hypoglycemia		
Hypoglycemia attitude and behaviour scale		
Avoidance	3	14
Confidence		
Anxiety		
Hypoglycemia confidence scale	1	9
DDS-2	1	2
PAID survey-20	1	20
PAID-5	1	5
PAID-1	1	1

DDS: Diabetes Distress Scale, PAID: Problem areas in diabetes

Table 4: Symptoms of diabetes distress

Sense of inability to cope with prescribed
Diet
Exercise
Monitoring
Investigations
Drug therapy
Fear of developing complications
Acute
Chronic
Hospitalization
Worry about health care
Access
Affordability
Quality
Dissatisfaction with social support from
Family
Friends
Community
Work place

DIFFERENTIAL DIAGNOSIS

The differential diagnosis includes not only MDD,[7,8] but also uncontrolled hyperglycemia. Comorbid endocrine/metabolic conditions such as hypothyroidism, hypogonadism, vitamin D deficiency, obesity, and obstructive sleep apnea should be ruled out before DD is diagnosed.[2] Nonendocrine comorbidities, including anemia, dyselectrolytemia, poor sleep hygiene, and poor physical condition are other causes which may lead to similar symptoms [Table 5].

CLINICAL IMPACT

DD is associated with low self-efficacy, poor adherence to suggested lifestyle regimes, poor glycemic control, and complications such as dyslipidemia [Table 6].[6]

MANAGEMENT

Management of DD is nonpharmacological in nature. The foundation of DD management is empathic and confidence-building communication by members of the diabetes care team. Up to 40% of persons with DD can improve without formal intervention.[9] Hence, a suggested strategy is "watchful waiting," while promoting lifestyle modification [Table 7].

Management is based on the concept of "Diabetes therapy by the ear," which includes listening to the patient, counseling,[10] and assisting in filtering nonscientific and irrational beliefs about the condition. Provision of diabetes education, self-management skills, coping skills training counseling and support is the best means of preventing, limiting and managing DD.

DD is often associated with change. Change is always associated with discomfort. One needs, therefore, to minimize the discomfort of change.[11] This can be done by involving the patient in a step-wise process of informed decision making and allowing choice as well as a review of such decisions [Table 8].

One must allow adequate contemplation of change, as per the 3 "*I*" strategy (inform, incubate, and initiate).[12] Positive motivation is an important aspect of therapy, which helps enhance acceptance of change. We suggest the 5 "*I*" Strategy as an approach to DD [Table 9]. This involves initiating discussion so as to identify possible stressors, informing the patient about methods to minimize DD, and helping incorporate positive coping mechanisms, so as to improve outcomes.

CAPACITY BUILDING

It helps to have a collaborative, inter-specialty approach to DD prevention and management. Diabetes care professionals need to develop certain basic biomedical as

Table 5: Importance of diabetes distress

A differential diagnosis is MDD
Endocrine and metabolic diseases causing similar symptoms must be ruled out
Considered "nonpathological"
A "normal" part of living with diabetes
Not a "comorbidity" of diabetes
Does not need to be labeled as disease
Does not need pharmacological therapy
Can be managed nonpharmacologically
Does not merit referral to mental health professional*

*May be handled by any member(s) of the diabetes care team.
MDD: Major depressive disorder

Table 6: Associations of diabetes distress

Insulin use
Depressive symptomatology
Poor adherence to
Meal planning
Exercise
Dyslipidemia
Poor glycemic control
Low self-efficacy

Table 7: Management of diabetes distress

Therapeutic patient education
Self-management skills
Diabetes counseling
Diabetes support
"Diabetes therapy by the ear"
Listen
Counsel
Filter unnecessary/potentially harmful messages
Minimizing the discomfort of change
Peer support
Lay educator support

Table 8: Minimizing the discomfort of change

Informed decision making
Shared decision making
Positive motivation regarding change
Allow contemplation of change (3 "I" strategy: Inform, incubate, initiate)
Inform regarding the need for change
Allow the idea to Incubate
Initiate the change
Allow choice of change
Break the change into easily manageable bits
Allow review of decision making if needed/indicated (s)

Table 9: Approach to diabetes distress: The 5 "I" strategy

Initiate discussion
Identify degree and source of DD
Inform means of minimizing DD
Incorporate healthy coping skills
Improve quality of diabetes care and support

DD: Diabetes distress

well as soft skills, to address DD properly [Table 10]. These include awareness of the condition and its differential diagnosis, ability to effectively communicate with the patient and offer appropriate interventions, as well as the foresight to refer to other health-care professionals when necessary.

Various acronyms such as CARES[13] and WATER[14] have been developed to help the diabetes care physician develop a patient-oriented approach and practice fruitful motivational interviewing. *CARES* is an acronym for the five qualities that help a diabetes care professional address DD effectively. These include confident competence, authentic accessibility, reciprocal respect, expressive empathy, and straight forward simplicity. *WATER* represents an easy to remember framework which helps facilitate successful conversation between patient and physician. It suggests five steps to be followed in every clinical encounter: welcome warmly, ask and assess; explain with empathy; and reassure and ensure return for the next consultation. These and other relevant tools, are included in Table 11.

Patients and family should also be empowered to address DD, by offering diabetes education and coping skills training, as required. Coping skills training can be taught by various methods. We have found the AEIOU system[15] useful in the clinic. This mnemonic suggests practicing the following actions in hierarchal or step-wise order: Assess and Analyze coping mechanisms, Eliminate of the negative coping strategies, Introduce and Internalize the positive coping skills, Observe the changes regularly, and Upgrade one's understanding continuously. Diabetes education should extend to the immediate family, colleagues at work, and other care givers too. The school teacher and bus driver of a child with diabetes, for example, should be trained in hypoglycemia prevention, identification, and management.

All stakeholders within the health-care system should be sensitized to the existence of DD, and its impact on diabetes care. Creating diabetes friendly atmosphere within health-care facilities, and outside of them, may help alleviate DD. DD can also be minimized if responsible patient centred care (RPCC) is followed in letter and spirit.[16]

SUMMARY

DD is an undesired, but real and likely part of life with diabetes. An in-depth understanding of the etiopathogeneis, clinical features, and diagnostic tests of this condition can help diabetes care professionals approach affected persons and care givers in a sensitive and empathic manner. Such a strategy will facilitate prevention, early identification and management of DD, and thus achieve optimal health outcomes.

Table 10: Skills needed to address diabetes distress

Awareness of DD
Ability to screen/diagnose DD
Ability to differentiate DD from depression
Ability to offer care for DD
Access to appropriate health care professional

DD: Diabetes distress

Table 11: Tools to enhance ability to handle diabetes distress

Physician
CARES: Patient motivation for insulin/injectable therapy
WATER (motivational interviewing): Motivational interviewing in persons with diabetes
Patient
Diabetes education
Coping skills training (the AEIOU approach)
Family
Coping skills training (the AEIOU approach)
Health care system
Patient friendly care
Responsible patient centered care (the 10R check list)

WATER: Welcome Warmly, Ask and Assess; Explain with Empathy; and Reassure and ensure Return for the next consultation, AEIOU: Assess and Analyze coping mechanisms, Eliminate of the negative coping strategies, Introduce and Internalize the positive coping skills, Observe the changes regularly, and Upgrade one's understanding continuously, 10R: Ten R.[16]

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REFERENCES

1. American Diabetes Association. Standards of medical care in diabetes-2017. Diabetes Care 2017;40 Suppl 1:S39-40.
2. Kreider KE. Diabetes distress or major depressive disorder? A practical approach to diagnosing and treating psychological comorbidities of diabetes. Diabetes Ther 2017;8:1-7.
3. Gonzalez JS, Fisher L, Polonsky WH. Depression in diabetes: Have we been missing something important? Diabetes Care 2011;34:236-9.
4. Fisher L, Hessler DM, Polonsky WH, Mullan J. When is diabetes distress clinically meaningful? establishing cut points for the Diabetes Distress Scale. Diabetes Care 2012;35:259-64.
5. Diabetes Distress: A Real and Normal Part of Diabetes. Available from: http://www.idf.org/diabetesvoice/issues/2016/issue-3/lawrence-fisher. [Last accessed on 2017 Mar 04].
6. Fisher L, Mullan JT, Arean P, Glasgow RE, Hessler D, Masharani U. Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. Diabetes Care 2010;33:23-8.
7. Polonsky WH, Fisher L, Earles J, Dudl RJ, Lees J, Mullan J, *et al*. Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale. Diabetes Care 2005;28:626-31.
8. Fisher L, Skaff MM, Mullan JT, Arean P, Mohr D, Masharani U, *et al*. Clinical depression versus distress among patients with type 2 diabetes: Not just a question of semantics. Diabetes Care 2007;30:542-8.
9. Hermanns N, Caputo S, Dzida G, Khunti K, Meneghini LF, Snoek F. Screening, evaluation and management of depression in people with diabetes in primary care. Prim Care Diabetes 2013;7:1-10.
10. Kalra S, Baruah MP, Das AK. Diabetes therapy by the ear: A bi-directional process. Indian J Endocrinol Metab 2015;19 Suppl 1:S4-5.
11. Kalra S, Kumar S, Kalra B, Unnikrishnan A, Agrawal N, Sahay R. Patient-provider interaction in diabetes: Minimizing the discomfort of change. Internet J Fam Pract 2010;8:1.
12. Kalra S, Gupta Y. Social pharmacology and diabetes. Indian J Pharmacol 2014;46:564.
13. Kalra S, Kalra B. A good diabetes counselor 'Cares': Soft skills in diabetes counseling. Internet J Health 2010;11:1-3.
14. Kalra S, Kalra B, Sharma A, Sirka M. Motivational interviewing: The water approach. Endocr J 2010;57:S391.
15. Kalra S, Kalra B, Sharma A, Sirka M. Coping skills training: The AEIOU approach. Endocr J 2010;57:S391.
16. Kalra S, Baruah MP, Unnikrishnan AG. Responsible patient-centered care. Indian Journal of Endocrinology and Metabolism. 2017 May;21(3):365.

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