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.\(^6,6\)

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.\(^7,8\)

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

<table>
<thead>
<tr>
<th>Physician</th>
<th>Limited access</th>
<th>Perceived inability</th>
<th>Poor communication skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with diabetes</td>
<td>Lack of motivation</td>
<td>Perceived inability to self-manage</td>
<td>Heavy burden of complications</td>
</tr>
<tr>
<td>Friends/family/community</td>
<td>Uncertain outcomes</td>
<td>Lack of understanding</td>
<td>Lack of support</td>
</tr>
</tbody>
</table>

Table 2: Precipitating factors of diabetes distress

<table>
<thead>
<tr>
<th>Change in life</th>
<th>Phase, e.g., adolescence, marriage, pregnancy, menopause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in disease state</td>
<td>Glycemic control, Extra glycemic complications</td>
</tr>
<tr>
<td></td>
<td>Acute, Chronic</td>
</tr>
<tr>
<td>Change in health care</td>
<td>Support, e.g., from family colleagues, System, e.g., HCP team, insurance</td>
</tr>
<tr>
<td>Change in disease management</td>
<td>Investigations, Treatment</td>
</tr>
<tr>
<td></td>
<td>Nonpharmacological, Pharmacological</td>
</tr>
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</table>

HCP: Health care provider
DIFFERENTIAL DIAGNOSIS

The differential diagnosis includes not only MDD, 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. Nonendocrine comorbidities, including anemia, dysselectrolyemia, 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].

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. 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, 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. 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). 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
Kalra, et al.: Diabetic 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

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 etiopathogenesis, 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

<table>
<thead>
<tr>
<th>Awareness of DD</th>
<th>Ability to screen/diagnose DD</th>
<th>Ability to differentiate DD from depression</th>
<th>Ability to offer care for DD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to appropriate health care professional</td>
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DD: Diabetes distress

Table 11: Tools to enhance ability to handle diabetes distress

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<thead>
<tr>
<th>Physician</th>
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<tbody>
<tr>
<td>CARES: Patient motivation for insulin/injectable therapy</td>
</tr>
<tr>
<td>WATER (motivational interviewing): Motivational interviewing in persons with diabetes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes education</td>
</tr>
<tr>
<td>Coping skills training (the AEIOU approach)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping skills training (the AEIOU approach)</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Health care system</th>
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</thead>
<tbody>
<tr>
<td>Patient friendly care</td>
</tr>
<tr>
<td>Responsible patient centered care (the 10R check list)</td>
</tr>
</tbody>
</table>

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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