Living successfully with type 1 or type 2 diabetes requires the very large task of managing a serious chronic condition. The tasks associated with diabetes can be complex and demanding and most people in their life journey with diabetes report great frustration with the burden of the disease. These physical and emotional demands generate emotional distress that can include worry, fear, sadness and anger regarding the emergence of complications, hypoglycaemic episodes, unpredictable blood glucose and feelings of ‘diabetes burnout’. Diabetes Distress is distinct from clinical depression, but high levels of distress are linked to poor glycaemic “management” and problematic self-care behaviours. Diabetes Distress often leads to the thought pattern of “I just can’t do this anymore” and for the primary diabetes healthcare provider, this is a signal that an open discussion can help individuals connect all the things they must ‘do’ with all of the emotions a person living with diabetes ‘feels’.

Lawrence Fisher, PhD, from the Department of Family and Community Medicine and the University of California, San Francisco and William Polonsky, PhD, at the Department of Psychiatry, University of San Diego California developed the Diabetes Distress Scales (DDS) for people with type 2 diabetes and the T1DDS for people with type 1 diabetes to help providers and their patients gain a better understanding of the emotional side of diabetes, recognize barriers to care and take steps for overcoming them. This month, Elizabeth Snouffer, Editor of Diabetes Voice had the opportunity to speak to Professor Fisher about Diabetes Distress (DD), the value of the Diabetes Distress Scales (DDS) and how healthcare providers can help people with type 1 and type 2 diabetes by acknowledging emotional distress and giving it some perspective.

Can you please define Diabetes Distress (DD)?

“DD refers to fears of complications, worries about hypoglycaemia 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. We also need to include family members that care for people with diabetes, including parents of children and partners of adults with diabetes, because they too can experience emotional distress related to diabetes.”

Who is at risk for DD?

“Everyone who lives with diabetes is at risk, but I would like to look at it a slightly different way. Everybody who lives with diabetes is going
to experience distress at some point in their diabetes career. One important question to ask is ‘where in the diabetes trajectory are people at the greatest risk?’ There are identifiable, targeted periods during which people have the greatest probability of feeling elevated levels of distress about their life with diabetes. For example, the following time points are often associated with increased levels of DD:

1. Around the time of diagnosis and at the time of learning how to self-manage diabetes;
2. At the emergence of a complication;
3. Adding to or switching a medication;
4. Switching healthcare plans;
5. Switching healthcare providers (finding a new doctor).

All of these are situations when some people experience higher levels of emotional distress. The best way to handle it is through prevention and helping people understand that how they feel about diabetes is as important as what they do. It’s important that people with diabetes understand and are prepared for those times when they will feel upset and concerned, and healthcare providers need to help patients recognise these periods and offer to help.”

Is DD considered a complication of diabetes?

“No, here’s why. The emotional side of diabetes is simply part of having diabetes. An individual may not be feeling particularly distressed at one point in time, but become upset and distressed at another point in time, perhaps around the time of the emergence of a complication, a switch in medication, or a change in a healthcare provider – there are all kinds of things that can be distressing about diabetes. If we consider DD a separate diagnostic category or a sub-category or complication, then DD can be seen as a complication and not as something that is simply part of having diabetes.

What we’re arguing for is that the management of distress should be a regular part of diabetes care since distress is so ubiquitous, and since it is to be expected that diabetes is tough. This means that along with attending to blood glucose numbers and disease management, we also need to pay attention to feelings – how people are managing the emotional side of diabetes. All three of these are important parts of good diabetes care.”

Since you brought it up, how does DD differ from clinical depression?

“That is a really good question and it comes up very often. Let me start by explaining that by ‘clinical depression’, we mean Major Depressive Disorder (MDD), a well-defined DSMV diagnosis. Among those with diabetes, the false positive rate of diagnosing MDD using screening instruments is enormous, ranging from 54-75% in our studies. The prevalence of classically defined MDD using a structured psychiatric interview - highly reliable and replicable is about 4-6% in people with type 1 or type 2 diabetes. The prevalence of MDD in the general community is also about 4-6%. This is not to say that people with diabetes don't have elevated depressive symptoms from time to time or that they never have MDD. Like all people, they do. But we find no significant data to support the conclusion that the rates of clinical depression are significantly higher in the total diabetes population than they are in community settings.

What we have instead are enormous rates of emotional distress about diabetes, which gets confused with depression. It’s much easier for a

“We are now beginning to understand that how people feel, affects how the body functions and vice versa.”
The seven major sources of DD among T1D adults

1. Powerlessness
   Feeling that one’s blood sugar numbers have a life of their own; e.g., “feeling that no matter how hard I try with my diabetes, it will never be good enough.”

2. Negative Social Perceptions
   Concerns about the possible negative judgments of others; e.g., “I have to hide my diabetes from other people.”

3. Physician Distress
   Disappointment with current health care professionals; e.g., “feeling that I don’t get help I really need from my diabetes doctor.”

4. Friend/Family Distress
   There is too much or too little attention paid to diabetes amongst loved one; e.g., “my family and friends make a bigger deal out of diabetes than they should.”

5. Hypoglycaemia Distress
   Concerns about severe hypoglycaemic events; e.g., “I can’t ever be safe from the possibility of a serious hypoglycaemic event.”

6. Management Distress
   Disappointment with one’s own self-care efforts; e.g., “I don’t give my diabetes as much attention as I probably should.”

7. Eating Distress
   Concerns that one’s eating is out of control; e.g., “thoughts about food and eating control my life.”

Where can healthcare professionals receive training so they can help patients with DD?

“This is a very difficult area. I find that this is something you just can’t lecture a healthcare professional about with any success. It really is a stylistic matter. This is about learning how to listen to your patients and identifying the underlying feelings that can drive distress and influence management. It’s about learning to stop doing all the talking. It’s about learning to ask open-ended questions. Finally, it’s about helping practitioners recognize that one of their most powerful tools is helping patients talk about the experience of having diabetes, identifying the specific sources of their distress, normalizing these feelings, and making all of this part of regular diabetes care.”

Can you discuss what has given evidence to the idea that patient quality of life is a better predictor of mortality and morbidity than some biologic measures?

“The classic example are the data on depression and myocardial infarction (MI) or heart attack in men. The data in this sphere clearly show that the presence of depression/major depressive disorder either prior or immediately after a first MI is a better predictor of one-year mortality than most other biologic variables. It’s thought to be linked to an underlying mechanism of inflammation. We are now beginning to understand that how people feel, affects how the body functions and vice versa.”

What is the Diabetes Distress Scale (DDS)?

“The DDS is a validated survey instrument that assesses diabetes-related emotional distress. Today, we have multiple distress scales for a variety of different people connected to diabetes, clinician to say ‘Oh, this patient is depressed’, so they either give the person an anti-depressant or refer them to a mental health specialist. In most cases, these individuals are simply experiencing high levels of emotional distress associated with their diabetes and its management.”
including scales for adults with type 1 diabetes (T1DDS), adults with type 2 diabetes (DDS), parents of adolescents with type 1 diabetes, and spouse/partners of adults with diabetes. The difference between the scale for adults with type 1 diabetes (T1DDS) and type 2 diabetes (DDS) has to do with the different sources of distress that each patient group may experience. Many healthcare providers in the current environment are no longer screening for depression, but they are starting to screen for DD, since DD has a much higher prevalence than depression in this population.

The diabetes distress scale can easily identify the primary sources of distress and it can become a tool for initiating a discussion about the emotional side of diabetes and the specific things about diabetes that are upsetting to a particular individual. If a patient scores high on feeling powerless, and most do, the healthcare provider can center the discussion around powerlessness and then engage with the patient to find ways to address the problem. The results from the distress scales are very actionable and help both the provider and the patient know what to focus on.”

What are the symptoms/signs from a doctor’s perspective that a person may be distressed?

“Well, for example, if a HCP observes a person who has been getting pretty good HbA1c results for months or years and all of a sudden there is a big shift in the wrong direction, focusing only on the numbers is a huge mistake. People get divorced, lose their jobs, experience other losses and real-life stressors, and these important life experiences rarely get addressed. It’s important to recognize that if there is a change in diagnostic test results, the clinician needs to open the door and ask, “How are you doing? Have there been any major disruptions in your life?” In addition, we believe that it is important to ask these questions at every visit. It is as important to assess how people are doing emotionally with their diabetes as it is to check their latest HbA1c. Some clinicians feel very comfortable asking these kinds of questions in a meaningful way and others do not. These are stylistic issues and it certainly doesn’t mean that everyone on the medical team needs to be talented in this arena, but someone on the medical team needs to have the skill and interest to address this important part of diabetes and its management.”

How do low DD, medium DD and high DD correlate with HbA1c outcomes? Does one cause the other?

“Very interesting question. They co-vary together over time. If DD goes up over time, you’ll usually see a corresponding increase in HbA1c and vice versa. To say one causes the other is a very different and complex question. We just published a paper that showed that individuals who are having problems taking medication have subsequently higher levels of distress, which is then associated with poorer HbA1c. It becomes a complicated picture of behaviour, feelings and the body’s reaction. It’s important to keep in mind that HbA1c is a biologic variable over a period of time, whereas emotions come and go much more quickly. Therefore, HbA1c is much more distal to the varying emotional experiences of diabetes. If a person has a hard week or two that results in a lot of distress with their diabetes, it may not have much of a direct effect in the short-term. Unfortunately, we are also seeing that chronically elevated levels of distress are significantly associated with poor HbA1c results over time.”

How can HCP’s utilise the distress scales for people with diabetes in the time available for each patient? There is only so much time and a lot to cover.

“What I like to suggest is to give all patients the scale at each visit. Even if they don’t meet pre-defined criteria for DD, the items in the scale can be a jumping off point for beginning a brief
conversation about how they are feeling about things. Often the patient will rate one or two items very highly and that can become the beginning of a conversation. Again, it’s asking very simple questions, like ‘I noticed you indicated frustration about …. What might be going on?’”

Can an HCP offer support and self-management improvements that will lessen DD? If yes, what are some examples?

“There are two parts to this. The first part is addressing the patient’s feelings about diabetes and the second part concerns addressing what can be done about it. But the first part gets missed a lot. It is very important to acknowledge that you cannot make people feel any differently than the way they do. There is no switch that can turn feelings off and on, as far as I know. People are going to get distressed, upset, frustrated, burned out, etc., and that’s OK – it is part of having diabetes. The problem is there is often no discussion about feelings and distress, and for some people there is no language for it, no way to talk about it. The scales give language to the emotions. So for example, it can be helpful if a provider asks, listens, acknowledges and reflects. It’s key for the provider to legitimize patient feelings, because it’s honest and real for the patient. In fact, it’s also important for the patient to realise that many people with diabetes feel the same way they do and this helps the person feel far less alone. What the provider is really doing is providing context, labelling and finally normalizing. If the provider helps the patient put their feelings in perspective, they become more tolerable and acceptable. This is all in part one of the discussion with the patient and, although it may sound like a lot to do, it is really a very brief conversation.
The second part of the conversation then turns to action. A provider might say, ‘Given how you are feeling, what do you think you need that would make things better, and how can I help?’

For example, if someone is feeling really scared because their vision is deteriorating because of retinopathy, then what could be suggested is ‘Let’s make an appointment with the ophthalmologist, and see where things currently stand, and then we can figure out what we can do about this.’ It’s important to create a behavioural outcome. What’s happening here is the HCP and patient are integrating feelings into action. Often, diabetes care only focuses on the doing, not on the feelings that drive behavior.

Overall, we have been discussing how DD is an expected part of living with diabetes, not a co-morbid condition requiring referral or specialized care. How well do you think this is accepted by the medical community today?

“I think it is becoming more and more accepted. My evidence for this is the number of requests we are receiving for the different diabetes distress scales that we have developed. As an anecdote, I was also surprised by the number of people who spoke to me after my presentation at the American Diabetes Association Scientific Sessions this past June (2016). Professionals were telling me that they were using the scale with success and that it was helping them pay more attention to the emotional side of diabetes by structuring the conversation – it made all of this practical and doable in the clinical setting. The distress scales also have helped healthcare providers feel less concerned about a major healthcare fear - opening a Pandora’s box of feelings and then either not knowing how to address the feelings or not knowing how to close the box during a brief visit.”

To access and download the Diabetes Distress Scales (DDS) and related scales, please go to the Behavioral Diabetes Institute web site by clicking on the link http://behavioraldiabetes.org/scales-and-measures/

Lawrence Fisher PhD, ABPP is a Diplomate in Clinical Psychology and an emeritus professor in the Departments of Family & Community Medicine and Psychiatry at the University of California, San Francisco. Professor Fisher has been the principal investigator of several NIH-funded research programs that addressed the personal, cultural, family and care-related aspects of diabetes self-management. He has also been the principal investigator of several NIH- and ADA-funded intervention studies to assess and reduce depression and distress among people with diabetes.