

In Brief

It is a well-known clinical reality that diabetes and depression are often seen together. What is not so well known or discussed is the phenomenon called “diabetes distress,” usually several feeling states related to depression but not severe enough to be diagnosed as such. This article explores the phenomenon of diabetes distress and offer clinicians some assessment and treatment intervention strategies.

Diabetes and Depression: Some Thoughts to Think About

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People with diabetes have double the odds of also having depression.¹ Approximately 10–15% of patients with diabetes meet the criteria for comorbid depression.^{1,2} Depression symptoms are present in about 15–20% of patients with type 1 or type 2 diabetes. Meta-analyses have linked depression in diabetes to hyperglycemia and suboptimal medical management.^{1,2}

The diagnosis and treatment of depression in people with diabetes follows much the same path as it does for those in the general population. However, the negative clinical implications for people with diabetes are greater because depression can negatively influence diabetes management and self-care behaviors.^{3–5} Interventions that focus on both pharmacological and “talk” therapies such as cognitive behavioral therapy seem to yield the best clinical results.^{6,7}

Given the close association between diabetes and depression, it is extremely important for clinicians not trained in mental health to become comfortably familiar with using clinical approaches that address the emotional and psychological needs of patients and their families. At the very least, it is crucial to know the importance of referring patients for appropriate mental health services if those services are not to be addressed in the medical clinic.

Distressed, But Not Depressed

The clinical guidelines for how to best serve the needs of patients suffering from clinical depression are well

documented in the literature. What is not adequately documented in the literature is the proper approach and treatment for individuals with type 1 or type 2 diabetes who are not clinically depressed but still experience feelings that are very close to depression often or occasionally in the course of living with their disease. This state sometimes is referred to as “diabetes distress” and is related to depression but not sufficiently severe to merit a diagnosis of depression.

The reason these patients do not show up on our health care radar is that, for the most part, they “cope” well. Such patients score high in coping abilities and tend not to talk much about having a difficult time.

How do these people cope? How do they think about diabetes and the impact it has on their lives? Of course, no one would argue that they do not have righteous cause to be upset, agitated, frustrated, or angry from time to time. The management regimen associated with achieving the level of diabetes control defined by the Diabetes Control and Complications Trial^{8,9} can be taxing, overwhelming, and exhausting for patients. What can clinicians do to be of more service to these patients, who do not “make a lot of noise,” who do what is suggested to them most of the time, but who still experience some emotional difficulties?

This article offers a discussion of this topic based on my experiences from being in the trenches, both professionally for more than 30 years, and

as a person living with type 1 diabetes for more than 48 years. The intention of this article is to serve as a clinical jumping-off point, to encourage further discussion and exploration that will lead to more effective ways to help and support patients and their families living with diabetes.

My focus will be on clinical parameters and perspectives that clinicians can use to help patients of this type become more effective in dealing with both the psychological and spiritual aspects of living with diabetes. It is meant to serve as a guide for diabetes clinicians who find themselves perplexed and frustrated by the psychosocial aspects of diabetes and unsure about how they can positively affect patients and their families. It will focus on the majority of patients with diabetes who are not clinically depressed but who still face four key feeling states—anger, fear, anxiety, and frustration—often or occasionally as a result of living with diabetes. Like diabetes itself, these feeling states become part of patients' day-to-day emotional landscape. Both patients and health care providers need a construct that defines positive approaches and strategies that can yield acknowledgment and understanding of and some relief for such emotional overload.

Address the Psychic Toll of Diabetes

Managing diabetes is like running a marathon, as opposed to a 50-yard dash. It is long and tiring, and it requires a strategy that takes the long term into account and depends on a sober accounting of available resources, both internal and external. Health care providers do not usually address enough with patients the heavy toll that “doing your best” to control diabetes can exact. Nor do we discuss what it takes to continue trying to do your best when you do not always succeed. For patients and their families, effectively managing diabetes on a daily basis takes tremendous focus and unwavering attention. The continual balancing of variables required to manage diabetes requires patients and their families to be “on” most of the time, even when they are nominally resting and relaxing.

Most patients realize the enormity of their task but tend to keep that awareness to themselves. However, most of the patients I have encountered in my many years of practice, when given the opportunity, do complain

and talk about what an exhausting and never-ending process diabetes self-care is.

The more clinicians come to understand that having these feelings is a part of any effective coping process, the more relieved patients will become and the less frustrated both groups will feel. The relief for patients usually comes when they perceive their health care providers as being attuned to the realities of living and coping with diabetes. The relief is about not having to live up to some artificially established benchmark for where they should be emotionally (e.g., happy, coping well, grateful, balanced) based on naive illusions and unrealistic expectations. Such expectations may be convenient to hold on to as ideals but are difficult for patients and providers alike to live up to.

Acknowledge Feelings of Powerlessness

Most people with diabetes experience a feeling of powerlessness. This is not to say they feel that they cannot affect their lives or the lives of those around them. Rather, it refers to their sense of being unable to prevent the onset of diabetes or, once diagnosed, to make it go away. On both an intellectual and spiritual level, many patients struggle with these feelings of powerlessness, saying, “If I’m so smart, I should be able to think my way out of this,” or, when dealing with numbers that do not correlate to behaviors, “I should be able to do better than this.” Parents trying to come to terms with the diagnosis of diabetes in their child usually experience a profound sense of powerlessness when they realize that there was nothing they could have done to protect their child from harm (developing diabetes) and cannot now make the “hurt” (diagnosed diabetes) go away.

I believe that powerlessness is the feeling that most accurately describes the core diabetes experience for patients and their families and loved ones. The experience has a different impact for people with diabetes than for those living with a relative or loved one with diabetes. We all have our own ways and styles of coping with this powerlessness as we perceive it. But almost everyone comes face to face with it on the journey of living with diabetes. Trying to come to terms with the daily struggle of chronic illness is both frustrating and exhausting.

Acknowledging one’s experience of powerlessness in the context of diabetes does not mean that one has no power to effect change in one’s own life. Rather, it means accepting that, over certain life events, one is powerless to change results that have already occurred. Primary to this principle, as applied in the field of recovery, is that, by acknowledging what one is powerless over, one can then determine in what areas one does have power to effect movement and positive change.

Crucial to any movement forward is this fundamental understanding. Once this understanding is gained, patients are free to actively participate in the construction of the rest of their lives. Although seemingly paradoxical, acknowledging powerlessness can be a tremendously empowering experience. Clinicians who understand this in the context of their own lives have much to offer to patients facing it for the first time.

Accept Reality

Complementary to this understanding is the ability to accept reality on reality’s terms and let go of the grasping for and holding on to wishes about how one would have liked things to turn out. If the spiritual and psychological response to the existential insult of diagnosis is a sense of powerlessness, perhaps the most effective coping mechanism for dealing with that powerlessness is the act of acceptance and letting go.

Diabetes care providers would do well to draw on the success of 12-step recovery programs, in which these principles are the keys to long-term addiction recovery. These principles have the potential for tremendously positive results when applied to diabetes because diabetes and chemical dependency have much in common. Both are chronic illnesses, require ongoing treatment, require daily active patient participation, and tend to decompensate when patients do not stay actively engaged in daily self-management. Diabetes and chemical dependency seem even more similar when one looks at the emotional responses of couples living with diabetes and those living with chemical dependency. Issues of codependency arise in both settings, and dysfunctional patterns of communication and interaction occur when couples are not in sync over either one.

Drawing on some of the principles of 12-step recovery as a clinical resource, then, would seem to make sense. I have integrated many of these principles into my counseling and education practice, and they seem to offer some relief from the burden of the chronic nature of diabetes and how it affects patients' lives. I mention this not as an absolute that has been scientifically proven, but rather anecdotally, as a point for clinicians to ponder. The following sections explore in more detail how the principles of acknowledgment of powerlessness and acceptance of reality can help patients with diabetes cope more effectively with the key four feeling states mentioned above.

Dealing with anger

Anger seems to be part of most patients' lives. Anger is a realistic psychological response to situations in which one feels powerless over certain people or events. It is neither good nor bad in and of itself; it is only a feeling. But it can be destructive to the core fiber of one's existence if not recognized and understood for what it is. An individual's personal and family history with anger has a lot to do with how he or she will deal with the feeling when it comes up.

For people dealing with diabetes, anger inevitably will come up. Patients feel angry about getting diabetes and about having to constantly monitor it. They also get angry about the drugstore running out of the supplies they've been ordering there every month for the past 2 years. They get angry about being at an event where there is no diet soda. They get angry when they feel embarrassed in public, when they have to stop playing in the middle of a high school football game because they feel low, or when they miss the signs of hypoglycemia and find themselves in an ambulance.

For families, there is anger (and anxiety) about a loved one who is not managing diabetes responsibly; for patients, there is anger toward nagging relatives. And for everyone, there is anger that there is no cure and anger that having diabetes is a constant annoying nuisance that gets in the way of the rest of your life.

Having diabetes provides a fertile substrate for anger, leaving patients more finely attuned to experiencing it when anything unexpected or unpleasant arises in daily life. Having

diabetes also means that, in many cases, you have already quietly used up your quota of "behaving." Many of my patients say that, deep down, they feel a sense of entitlement, a sense that they should be absolved of ordinary responsibilities such as taking out the garbage or paying the bills because of the extraordinary responsibilities they must take on in dealing with diabetes. With such an outlook, it doesn't take more than a little push to trip the anger wire.

Each person reacts differently to different situations. What makes me angry will not necessarily make Tom angry. But, if we both have diabetes, we will most likely both feel angry with some aspect of it or another with some frequency. We may not be angry enough to lash out or to feel entirely overtaken by anger, but the feeling is there, even if only on the fringe of consciousness, and it takes up valuable real estate on our emotional hard drives.

It is important to convey to patients and to their families and loved ones that it is natural to be angry sometimes about some things related to living with diabetes. Clinicians can help alleviate some of the intensity of their patients' anger by initiating conversations that convey their understanding (e.g., "You must be angry about having to do so much to manage your diabetes. I'd be interested in hearing how you deal with it all the time."). Put off discussing the monitoring results or lab values or carbohydrate counting if necessary to spend some time talking about these feelings. Your patients will appreciate it.

Clinical success here is not so much about making patients' anger go away as it is about helping patients construct a framework for how to handle their anger when it arises. Patients need tools to help them make sense of their feelings. They need to be able to vent and receive validating responses. And they need to find positive, functional ways to channel their energy instead of giving in to the negative impulses that anger can engender.

Facing fears

Often, patients who seem angry on the surface are really feeling fear deep down. For many people, it is easier to be angry than to admit that we're afraid of something. Likewise, fear can be masked as denial, irresponsible management, frustration, or unexplained sadness. As with any

strong feelings, fears left unattended will often take on some other form. Addressing our patients' fears in a sensitive and compassionate way will make all the difference in helping them achieve a more balanced life and come to view their time with us as truly healing in the larger sense of the word.

There are many understandable fears related to having diabetes. For patients, these include fear of hypoglycemia, of injections, of incorrect dosing, of not waking up. There is also fear of intimacy, fear regarding sexual performance, fear of dependency on others, fear of being judged, and, for families, fear of not being supportive enough or not doing the right thing. In the longer term, there is fear of complications, fear of living in infirmity, and fear of not being able to live out one's dreams for retirement.

As clinicians working with people with diabetes, we need to feel comfortable talking about such fears. We need to achieve a delicate balance in which we neither indulge them too much nor completely disregard them. A frank discussion, starting with the simple question, "What things are you afraid of regarding your diabetes?" is a good place to start.

It is important to remember that the problems do not necessarily need to be solved right at once; they only need to be discussed. Fear related to diabetes tends to be chronic in nature; the most important thing to do is to initiate the discussion so that patients and their families feel that it is okay to talk about their fears and that they do not have to suppress their fears and pretend to be coping better than they are. Patients need to know that, given the realities of the disease, it is normal to feel afraid from time to time. It is our job as clinicians to help patients develop an internal space where they can appropriately store their feelings, to be taken out and examined when they are able, rather than just suppressing them.

Handling anxiety

Anxiety is related to fear and anger in intimate and deep ways. According to the dictionary, the definition of anxiety is "an unpleasant state of mental uneasiness or concern about some uncertain event." Most people become anxious over certain things, but the intensity of the anxiety typically corresponds to the situation.

In diabetes, there is plenty to be worried about. And again, depending on individuals' internal resources, they may be able to cope effectively most of the time. At other times, the anxiety may become too much, and psychic difficulties may result and be expressed in ways unique to the individual but including restlessness, anger, fear, grouching, difficulty focusing, and inability to complete certain tasks. Many people with diabetes, particularly the group of patients we have been discussing who are not quite diagnosable with an emotional disorder, may be able to cope, to cover up their feelings, and to continue moving on with their lives. But there is often still an internal psychic cost associated with the intensity of the eventualities worried about, be they going blind, losing limbs, suffering with failing kidneys, or simply receiving "bad" test results.

Again, the qualitative experience for patients will be better if they are working with clinicians who are aware of the likelihood and reality of these feelings arising in the course of daily life with diabetes. Addressing such issues during regular office visits may not mean having specific discussions about them, although such discussions may be necessary at times. However, it is most important to simply be aware that anxieties may exist for patients not as a separate dysfunction, but rather as a normal part of their larger effort to manage several intense feeling states 24 hours a day, 7 days a week.

Validating frustration

I do not know of any person with diabetes who does not have to deal with frustration as one of the most prominent states of daily life. However, every aspect of the diabetes management routine provides patients and families with an opportunity to grow spiritually from dealing with frustration.

Frustration can stem from such common occurrences as running out of blood glucose test strips or medication, not being able to get a clinician or educator on the phone, not having glucose tablets handy when experiencing a low, being stopped at airport security because of an insulin pump, or having to wait an excessively long time at a clinician's office. Add to that the frustration that arises when trying to describe what living with diabetes is like to someone who does not quite get it or dealing with public ignorance about the difference between type

1 and type 2 diabetes. The frustration mounts for patients who wake up with a blood glucose level of 295 mg/dl when they went to bed with a reading of 95 mg/dl and only dreamed of eating pizza! Wanting to achieve better diabetes management but being unable to do so because of stress related to work and life events leads many patients to feel at times that they simply cannot handle one more thing.

Clinicians can support patients enormously by being aware of these realities and by bringing them up in casual, yet intentional ways. This tells patients that you recognize just what their difficulties are. Again, the clinician's job is not so much to make the sources of their patients' frustration go away, but rather to bear witness to the fact that they exist and affect patients' lives in important ways. It is that bearing witness, that empathy, more than the ability to fix things, that is the clinical touch that can aid patients' overall healing process. In diabetes care, much of the work involves healing, not fixing.

Conclusion

Clinicians dealing with patients who struggle with difficult feeling states in the course of their daily life with diabetes must strive to become more comfortable with allowing their patients and themselves the luxury of being imperfect. Clinicians who can let go of their own sense of inadequacy because they cannot "fix" their patients' problems can retract the delusions that they may be projecting onto their patients around being perfect and embrace imperfection as an acceptable state with regard to the situation. The first step to being able to help our patients is to look at ourselves openly and honestly to evaluate our expectations of ourselves and come to terms with our limitations as human caregivers.

I believe that most patients with diabetes, after accepting the fact that their condition is not going away, do not want to be "fixed" as much as they want to be listened to and "heard." It is your listening, your bending of your ear to the tune of their stories, that validates their struggles and frustrations as being real and courageous. That is where I believe the healing process occurs. Providers and patients who can achieve this level of understanding and support make the emotional space available to struggle

honestly with achieving the best possible diabetes control.

There is no moral valence to feelings; they are all good. They serve as important indicators of how well we are coping and achieving a sense of balance in our lives. They are our keys to living full, three-dimensional lives in connection with others. Feelings are windows into ourselves and others, reflected and projected as we interact with each other and face life's events. Patients should be able to expect their clinicians to help them navigate the feelings associated with diabetes by providing them with constructs and frameworks that will allow them to learn and grow.

Again, it is not about making the negative feelings go away, but rather about providing patients with opportunities to discuss and explore these feelings and thus move on to negotiating and wrestling with them in a way that allows life to continue. Fighting or suppressing negative feelings usually results in something akin to the pudding scene in the film "Sleeper," in which Woody Allen tries to beat the pudding with a stick; the more he beats it, the more it grows! Successful diabetes care and self-care begins with healing, not fixing. The role that each of us assumes in facilitating that process for our patients and for ourselves is paramount.

References

- ¹Ryan J, Anderson BA, Freedland K, Clouse R, Lustman P: The prevalence of comorbid depression in adults with diabetes. *Diabetes Care* 24:1069-1078, 2001
- ²Katon W, Von Korff M, Lin E, Simon G, Ludman E, Russo J, Ciechanowski P, Walker E, Bush T: Stepped collaborative care for primary care patients with persistent symptoms of depression: a randomized trial. *Arch Gen Psychiatry* 61:1042-1049, 2004
- ³Cohen ST, Welch G, Jacobson AM, De Groot M, Samson J: The association of lifetime psychiatric illness and increased retinopathy in patients with type 1 diabetes mellitus. *Psychosomatics* 38:98-108, 1997
- ⁴Kovacs M, Mukerji P, Drash A, Lyengar S: Biomedical and psychiatric risk factors for retinopathy among children with IDDM. *Diabetes Care* 12:1592-1599, 1995
- ⁵Leedom L, Meihan WP, Procci W, Zeidler A: Symptoms of depression in patients with type II diabetes mellitus. *Psychosomatics* 32:280-286, 1991
- ⁶Lustman P, Griffith L, Friedland K, Kissel S, Clouse R: Cognitive behavior therapy for depression in type 2 diabetes mellitus. *Ann Intern Med* 129:613-621, 1998

⁷Jacobson A, Weinger K: Treating depression in diabetic patients: is there an alternative to medications? *Ann Intern Med* 129:656–657, 1998

⁸DCCT Research Group: The effect of intensive treatment of diabetes on the development and progression of long-term complications in

insulin-dependent diabetes mellitus. *N Engl J Med* 329:977–986, 1993

⁹DCCT/EDIC Research Group: Intensive diabetes treatment and cardiovascular disease in patients with type 1 diabetes. *N Engl J Med* 353:2643–2653, 2005

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