



## DIABETES BURNOUT – REVIEW

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Diabetes burnout could be a major risk for poor metabolic control and long term diabetes complications. When not identified, explained and understood, diabetes burnout is very destructive, often deadly. What happens when a person will often participate in self-destructive behaviour? Profound, subtle and chronic physical, mental and social interconnections occurs in diabetes and may become overwhelming for both patient and physician. A realistic and sincere approach, leads to the conclusion that for some, life with diabetes is not easy at all. Given that diabetes can require a great deal of personal effort and a large number of decisions every day, it is remarkable that anyone is able to manage diabetes successfully day after day, year after year. Over time, the patient can reach a state of exhaustion and helplessness comparable to burning to the ground – burned out. Therefore, burnout is found mainly in patients who dropped out of medical care and thus ignoring the disease for years, perhaps decades, until complications began. Moreover, this feeling of exhaustion can overwhelm even the enthusiastic physician called to manage “insolvent problems”. The professional burnout which provides failure of the therapeutical relationship, close and amplifies the cycle of deliberate and severe neglect. The point is that we suspect the existence of a substantial subgroup of diabetics and physicians who suffer in silence from burnout.

Diabetes Burnout is frequent in medical practice and largely responsible for the discrepancies between, on the one hand, the scientific, technical and therapeutic arsenal and, on the other hand, the unacceptably high number of patients with diabetes mellitus (DM) who do not benefit and therefore with poor metabolic control and at high risk of devastating complications. If the diagnosis of diabetes is very simple and cheap, the treatment is neither simple nor cheap.

The real problem is that physicians are trained to intervene promptly in acute situations, to use all resources to solve the problem, and to change strategy in order to take control in case of failure, relapse or complication.

Because diabetes is a chronic condition, except for exacerbations, physicians control the disease through the patient only. The latter must become a co-therapist despite the lack of academic training for being the carer and cared person in the same time.

Theoretically, according to traditional diabetology, for a favorable and uncomplicated evolution, “right” knowledge about the disease, early therapeutic approach, fairness and consistency in attitude, good habits, tools and skills in diabetes management would be sufficient. Basically, from the patient’s perspective, a sincere and realistic observation reveals that for some people life with diabetes is not easy at all, simply because medical advice cannot always and strictly be met. Anyone is able to manage diabetes successfully day after day, year after year.

Unfortunately, in such a confrontation it is much easier, for both patient and physician, to neglect this aspect of diabetes care, which will lead to a disjunction between medical versus personal, and theoretical versus real diabetes.

### BURNOUT DEFINITION

The name of burnout was first used in 1940 in aviation to designate a point where jet engines stop working. The term was then translated as meaning a heavy monotonous and frustrating job, where the

person works harder and harder each day, without satisfaction, where everything seems that actions didn't make any real difference, with one's own worth being questioned, strong feelings of guilt about failure, hostility, and aggressiveness towards others. Those people become completely involved and take home from work their worries and extra work until they "catch fire and burn like phosphorus. After the disaster remains a great emptiness"<sup>1</sup>.

### **DIABETES BURNOUT DEFINITION**

By analogy, diabetes is like "a full-time job you didn't want and can't quit"<sup>2</sup>.

All of the unrewarded efforts required of people with diabetes can sometimes lead to "diabetes overwhelms" or "burnout" – a state in which patients grow tired of managing their disease and then simply ignore it for a period of time, or worse, forever – "I quit attitude".

William Polonski, an active researcher in behavioral medicine describes with subtle irony the burden of diabetes self-care:

"From the outside diabetes looks like it should be fairly simple. All you have to do is: take your oral medication or insulin every day, at the right time and in the right amount, eat perfectly without cheating, check your blood glucose regularly, don't gain or lose too much weight, exercise frequently, include these tasks in your everyday life so that your blood glucose levels never get too low or too high, stay vigilant to avoid problems, continue to do all of this every day for the rest of your life"<sup>3</sup>.

Joan Williams Hoover, who first developed the concept of diabetes burnout, describes how diabetes can require a great deal of personal effort and a large number of personal decisions every day:

"And even the constant need for decisions might be tolerable, if only the results were predictable. Few things generate burnout like the awful frustration of having followed instructions and done everything just right and still be failing to get diabetes into control. At those times it seems no use to continue to try"<sup>4</sup>. For some people the frustrations can lead to feelings of helplessness and depression. In other words the inability to get a good glycemic control determines negative attitudes

and beliefs towards diabetes, leading to a downhill spiral that can affect the performance of self-care.

The point is that diabetes burnout could be a major risk for poor metabolic control and long term diabetes complications, as well as too many people have chosen to ignore their diabetes for years or decades and suffer in silence from burnout.

Some statistics from a USA nationwide survey before 1999 may surprise: 21% type 1 DM, 41% type 2 DM using insulin, 76% type 2 DM using oral medication reported that they never checked their blood glucose levels<sup>3</sup>.

From 1994 to 2010, the age-adjusted percentage of adults aged 18 years or older with diagnosed diabetes performing daily self-monitoring of blood glucose increased by 27.9 points, from 35.7% to 63.6%<sup>5</sup>.

The difficulty to manage diabetes effectively that most people with diabetes report is illustrated by Richard Rubin's experience at a lecture: "When I asked the audience of over 2000 people with diabetes to rise a hand if they felt they did everything they should do to manage their disease, two hands were raised. One of these individuals had been diagnosed with diabetes for 1 week, and the other for 2 weeks!"<sup>6</sup>.

### **HOW TO RECOGNIZE DIABETES BURNOUT?**

An important issue is to recognize patient Burnout. What happens when a person will often participate in self-destructive behavior? Some skills meant to enable health care professionals to gain insight into the perception of people with diabetes could be integrated into clinical care.

The more items on the following list accurately describe the patient's strong negative feelings about diabetes, the more likely it is that the patients have burned out on diabetes:

- feeling overwhelmed and defeated by his/her diabetes;
- feeling angry about diabetes;
- feeling that diabetes controls his/her life;
- feeling alone with diabetes and feeling that no one understands;
- feeling ashamed about diabetes and keeping it a secret;
- worrying that he/she is not taking care of diabetes well enough, and yet feeling hopeless, unable to change;

- feeling guilty and frightened about his or her poor control;
- feeling exhausted with decreased capacity of action;
- feeling that proper self-management is not worth the effort;
- admitting to chronically poor self-care and poor glycemic control;
- avoiding blood glucose monitoring or doctor visits that might give feedback about the consequences of poor self-care;
- telling him/herself that diabetes management is not important, that living with high blood sugar is not a problem and complications can't happen to him/ her;
- thinking about diabetes as little as possible.

Some behavioral and emotional associations might outline a risk profile: feeling that he/she must try constantly to be perfect or that he/she must dedicate his/her life to caring for others; multi-tasking women – as the family caregiver, they have a harder time prioritizing their own needs. Persons who want to do everything alone with too little support may be especially prone to burnout.

Profound, subtle and chronic physical, mental and social interconnections occur in diabetes and may become overwhelming for both patient and physician.

When not identified, explained and understood, diabetes burnout is very destructive, often deadly.

We list below some possible assessment errors that health care providers could make in their clinical approach:

- Ignore emotional reactions to diabetes or depression
- Inability to recognize feelings about diabetes
- Embarrassment to discuss about feelings
- Labeling the patient as: ignorant, non-compliant, stupid, less frightened about complications or lacking willpower or personal discipline.

Diabetes burnout can be whatever it means to the patient. Totally giving up form of burnout is not really the most common form. It may be a subtle lack of stamina for facing the daily struggle, or an overwhelming feeling – “Ugh, this is so much work, every day!”; or fingers hurting from constant finger pricks, or being incredibly stressed out every time he/she has to contemplate the carbohydrate counts in his/her lunch; feeling guilty every time he/she eats something a “diabetic shouldn't eat”... but feel too frustrated to choose differently.

Our statistics in “Nicolae Paulescu” Institute survey show that 25% of inpatients with diabetes reported levels of emotional exhaustion between moderate and high.

When considering patient compliance healthcare professionals should be aware of this phenomenon as well as their own attitudes and approaches toward the patient.

### **CAN DIABETES BURNOUT BE OVERCOME?**

People generally adapt well over time to life-changing situations and stressful conditions. What enables them to do so? It involves **resilience**, the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress – such as family and relationship problems, serious health problems or workplace and financial stressors. It means “bouncing back” from difficult experiences<sup>7</sup>. The term is used in navigation and means saving a sailor who has fallen into the water: “Risolire”. Resilience allows a person or group of people to rebound from illness, failure, fall, misfortune, and hardships and recover, starting afresh.

Resilience means facing life's difficulties with courage and patience – refusing to give up, and the ability to work with adversity in such a way that one comes through it unharmed or even better for the experience. This process requires time and effort and engages people in taking a number of steps.

### **HOW CAN DIABETES BURNOUT BE OVERCOME?**

Help the patient to avoid seeing crises as insurmountable problems. He/she can't change the fact that highly stressful events happen, but can change how to interpret and respond to these events. Ask the patient to try looking beyond the present to how future circumstances may be a little better and to note any subtle ways in which he/she might already feel somewhat better as he/she deals with difficult situations. To alleviate diabetes burnout several strategies are recommended, each one presenting different challenges:

- Establish a collaborative relationship with patients
- Relieve the stress of “trying to achieve perfection”

- Pay attention to strong negative feelings about diabetes
- To promote “success experiences”
- Take time to review all self-care behaviors
- Identify the errors and reinforce therapeutic formation
- Identify personal barriers to good self-care
- Engage patients in active problem-solving
- Get some support.

### **Establish a collaborative relationship with patients**

First, health care providers must recognize the need to see their patients with diabetes with new eyes: not “like a collection of organs at risk and a source of blood and urine”. We must help our patients to see us and themselves in a different light, as well.

Second, it’s very important to establish a collaborative relationship, to be respectful of the patient’s struggle with diabetes self-care and clearly delineate the areas of responsibility for the patient. The latter must understand that he/she is not guilty of the development of diabetes but it is his/her responsibility to prevent early appearance of complications.

Focus on promoting subjective adherence rather objective compliance may be very helpful. Encourage active patient participation in decision making, goal-setting, problem solving.

### **Relieve the stress of “trying to achieve perfection”**

Many people with diabetes feel like they should always have blood glucose readings in their target range, and become frustrated when, despite their best efforts, they don’t reach their goals. Good diabetes care doesn’t mean being “perfect” but staying motivated!

### **Be sensitive to the existence of emotional responses to diabetes**

Listen well and respectfully rather than leap quickly to find solutions for the patient’s feelings.

Rule out depression as a cause or magnifying factor. If not dealt with, the depression can become even worse and affect every aspect of a person’s life.

Normalize the patient’s negative feelings (fear and denial, hyper-vigilance, anger and acting out, guilt and recrimination, anxiety and depression

disorders), reassuring the patient that such feelings are common and understandable responses.

Because there are many long term benefits but not very many immediate benefits to taking care of diabetes, no one feels motivated for diabetes care if the immediate costs seem to outweigh the benefits. On the other hand, patients need to feel cared about and respected.

We must pay consideration and respectful attention to blood glucose records and to the list of any other concerns he/she may have about how diabetes is affecting his/her health.

Establish continuity of regular care and contact.

### **Take time to review all self-care behaviors and identify the errors and barriers and make a list of obstacles to the best possible self-care (Table 1)<sup>3</sup>**

*Table 1*

The barriers to good self-care

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<b>Personal barriers</b>
Lack of knowledge about diabetes
Inaccurate health beliefs
Negative feelings about diabetes
Poor coping styles
Unrealistic expectations about self-care
Eating disorders
Chronic depression
Fear of hypo/hyperglycemia or weight gain
<b>Interpersonal barriers</b>
A poor relationship with the doctor
Family confusion about self-care responsibility
Dedicating his/her life to caring for others
Too little support
Too much support
Family conflict
<b>Environmental barriers</b>
An unstructured life
Financial burdens
Chronic life stress
Competing priorities

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### **Reinforce therapeutic formation**

Very often the patient has a negative perception of failure and cannot determine a hierarchy of errors. All seem to be just as serious with negative anticipation and inability to find what might help with unreasonable thoughts that are not connected quite rightly to reality.

The way in which errors are handled is crucial in the process of therapeutic formation. Therefore it’s

important to teach patients that all learning is a trial-and-error process and to empower him/her to try and see what happens (experience + feedback) and to expect difficulty and error, even to plan ahead for them. In addition, it's necessary to teach their brain to calm itself at the right moments.

### **To promote success experiences**

Check for depression and knowledge about diabetes and reconsider the clinical reasoning and therapeutic strategy. Then engage patients in active problem-solving one by one, helping the patient to prioritize the self-care changes and to engage actively in solving these problems.

Encourage the patient to start with only one selected change and focus on building that behavior into a regularly established habit. Considering simple environmental solutions may be very helpful.

Preparing a plan that really works is another important step.

Take it slow and be patient. Set achievable goals.

Be as specific and creative as possible. Focus on immediate concrete action. Diabetes self-care goals must be: realistic, simple, concrete, specific and measurable.

Much of patient resilience comes from the community – from the relationships that allow their members to lean on each other for support when they need it.

### **Stress-management strategies**

With diabetes, it's important for the patient to put him/herself first<sup>5</sup>. Accepting circumstances that cannot be changed can help to focus on circumstances that the patient can alter. An optimistic outlook enables the patient to expect that good things will happen in life. Advise patients to try visualizing what they want, rather than worrying about what they fear.

We list below some major strategies for coping with stress:

1. Begin a regular exercise program
2. Pick two priorities a day
3. Cut calories, not pleasure. Eat one serving, not two
4. Challenge your automatic way of thinking about stress
5. Make a friend
6. Give in to frustration

7. Take a break every day (relaxation exercises)

8. Get perspective: let go of what's wrong and focus on what has gone right!

9. Celebrate your wins

10. Take a diabetes vacation

11. Avoid the dangerous approach to stress-management: drugs and alcohol.

Every diabetic needs a break from managing the disease. Warning: that doesn't mean giving up on taking his/her meds.

A successful break involves four steps: planning, limiting its length, keeping it safe and making it restorative.

### **THE KEY TO SUCCESS**

In a recent survey, a group of DCCT participants were asked about the amount of personal effort required to reach and maintain near-normal blood glucose levels day after day for an average of 8 years. The DCCT (Diabetes Control and Complications Trial) (1982–1993) was designed to test the glucose hypothesis and determine whether the complications of type 1 diabetes (T1DM) could be prevented or delayed. It was a controlled clinical trial in 1,441 subjects with T1DM comparing intensive therapy (INT), aimed at achieving levels of glycemia as close to the nondiabetic range as safely possible, with conventional therapy (CON), which aimed to maintain safe asymptomatic glucose control. INT utilized three or more daily insulin injections or insulin pump therapy guided by self-monitored glucose. How did they manage to succeed and what type of support did they find most helpful?

During the study all participants had access to the finest medical care, education and guidance. But the secret of the DCCT that helped the participants to keep up their efforts over the years was the “nondirective support” – in the sense that the staff tended to work with the participants in a friendly and respectful fashion, with frequent contacts, helping them to make their own decisions rather than telling them what to do<sup>3</sup>.

### **PROFESSIONAL DIABETES BURNOUT**

In 1974, the psychoanalyst Herbert J. Freudenberger defined burnout as “the extinction of

motivation or incentive, especially where one's devotion to a cause or relationship fails to produce the desired results." In his book, Freudenberger compared job burnout to a burned-out building: "the outer shell may seem almost intact. Only if you venture inside will you be struck by the full force of the desolation"<sup>9</sup>.

According to Christine Louise Hohlbaum\*, the workload isn't enough to spark burnout. You can have a lot to do and still feel fulfilled and satisfied. But if your boss is treating you unfairly, then your workload becomes a burden, not a source of joy and fulfillment."

Johansson in the UK show that more than 60% of diabetes care staff reported levels of emotional exhaustion between moderate and high<sup>10</sup>.

Why evoke this syndrome in caregivers that, although suffering, seem to function properly?

First to help the caregivers themselves. Some are involved in diabetes care with increased levels of frustration, blaming themselves for the failures of diabetes care:

"What I am doing wrong? This patient can't learn this? If only he would comply? He isn't intelligent enough. Why can't he get this right? He says he does everything I tell him and it's still no better..."

Second, because a saturated, exhausted, overworked caregiver will take distance and tend to address the disease as a routine, with complete non-involvement. It is known that a collaborative relationship between doctor and patient could be a therapeutical instrument and patients that experience lack of attention by a caregiver have a mediocre observance of their treatment.

### THE "THREE R" APPROACH

Dealing with burnout means:

- **recognize** (watching for the warning signs of burnout);
- **reverse** (undo the damage by managing stress and seeking support);
- **resilience** ( build resilience to stress by taking care of physical and emotional health).

\* Author of *The Power of Slow: 101 Ways to Save Time in Our 24/7 World*.

### Warning signs of professional burnout:

- Disengagement
- Emotions are blunted
- Feeling of helplessness and hopelessness
- Loss of motivation, ideals, and hope
- Detachment and depression
- Life seems not worth living.

Identification and treatment of patients and caregivers with burnout could lead them to overcome naïvety in the field of diabetes care and bridge the gap between psychological research and management of diabetes. It could lead to a radical change of clinical reasoning, and bring a ray of hope for those affected.

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