

# Patient Burnout, and Other Reasons for Noncompliance

Joan Williams Hoover

*Patients, as well as healthcare professionals, can suffer from "burnout." The author suggests that the constant stress and frustration of diabetes management can lead to "patient burnout." When considering patient compliance healthcare professionals should be aware of this phenomenon as well as their own attitudes and approaches toward the patient.*

Recently, healthcare professionals have been playing with a buzzword called "burnout." Burnout usually describes a condition caused by prolonged living with unrelieved stress. People who are candidates for burnout eventually find their work to be physically, mentally, and emotionally exhausting. Once they reach the state of burnout, they may become listless, indifferent, forgetful, careless, or bored. This unfortunate condition of burnout is receiving sympathetic attention in many professional circles.

I propose that diabetic patients also experience burnout. The symptoms of this burnout are readily identified, but for some reason they are usually misdiagnosed as "non-compliance." Let me explain the correlation between patient and professional burnout, so that next time someone says, "He used to be such a good diabetic. I just don't know what happened to him," you can step forward with the same kind of non-judgmental help and compassion that you would expend on one of your colleagues.

People who live with diabetes always live with unrelieved stress. Throughout each day, no matter what else they are doing, they must be tuned-in to their own bodies in order to anticipate the need for more insulin,

more food (quick sugar), or even exercise. For the person with diabetes a simple headache must be analyzed. He needs to know why he has the feeling? What caused it? Is it potentially threatening? He may then have to take immediate and appropriate action. The stress part for people with diabetes, is that this process must take place 24 hours a day.

As well as anticipating insulin reactions, infections, and illness, and making the necessary adjustments, there are smaller, daily frustrations. He must resist the temptations of sweets, alcohol, and too much food, as well as cope with the awkward social situations such actions create. Try telling your hostess that you can't eat her famous blue ribbon birthday cake just baked "especially for you."

For each diabetic person the ultimate stress is to live with a constant, subliminal fear of the unknown: those complications which lurk in the grey mists of the future. By explaining complications we allow people with diabetes to be battered by their own futures, all in the name of helping. None of us knows what lies ahead, and it's just as well. What purpose would have been served if 20 or 30 years ago someone had said to Princess Grace, "One day you'll drive off the side of a mountain and be killed. We don't know when . . . but you'd better be careful!" That's ridiculous and ghoulish, and yet we say the equivalent to diabetic patients every day, and thus add to their stress.

Burnout candidates are said to be perfectionists. Doesn't "perfectionist" describe the ideal diabetic patient? I believe "a perfectionist" is the behavior goal of most of our education programs. Check this on your evaluation

sheets. "Patient always tests and records. Always rotates injection sites. Always eats on time. Never deviates from meal plan, etc." The compliant patient is a perfectionist . . . and perfectionists burnout.

Students of burnout observe that perfectionists don't like delegating work or responsibility. Unfortunately the work or responsibility of daily management of one's own diabetes is impossible to delegate. Even well meaning parents, who attempt to assume that responsibility for their diabetic children for any length of time, only succeed in creating emotional and developmental problems.

When you are next faced with a non-compliant patient, stop and consider if what you are observing may simply be a good, textbook case of burnout. From the moment a person develops diabetes, for 24 hours a day, 365 days a year, for the rest of his life, he is responsible for managing the unmanageable, controlling the uncontrollable, and coping with the incurable — his diabetes.

The diabetes education dropout you see before you is probably someone who is just tired of the daily coping. To really help him will be your greatest challenge. No handy check list or audio-visual program is going to help you. You're going to have to write the book for each individual person, and you won't succeed until you can truly understand his feelings and emotionally stand in his shoes. You will note, at once, that the standard, prescribed treatment for burnout is simply not applicable to your patient. The usual recommendations are:

1. Cut back on the stressful tasks.
2. Lessen the care and concern.
3. Avoid the people who are causing

the stress (perhaps a health care professional).

4. Take a vacation from the work. Remember that no patient wants "to learn to live with diabetes." What he wants to learn is how to live *without* it.

At any rate, a person with diabetes who followed the advice outlined in those four, sure-fire methods of coping with burnout, would be considered a full-blown, non-compliant patient.

What is the diabetes educator's role in patient compliance? First, to determine whether or not the patient has an obligation to comply with the prescribed therapy, and if so, whether the obligation is to his caregiver or to himself. Second, to identify the reasons for non-compliance. These may include the patient's other priorities, emotional barriers, or lack of comprehension, as well as burnout. Third, to examine the effectiveness of the broad spectrum of motivators which range from fear and threats to love and compassion.

The answer to the first question is NO! The patient has no obligation whatsoever to be compliant. He is a consumer, and is buying a service of instruction and advice. Once he has paid your bill what he does with the information is up to him. In my opinion, one of the prime reasons for non-compliance is that the patient's priorities for himself are simply not the same as your priorities for him. Most people led full and busy lives before they became diabetic, and they have no intention of changing all of that just because their beta cells are failing.

Lastly, the broad spectrum of motivators used by health care professionals often becomes a bit impersonal. Your job is to transmit information to the patient, but a transmitter is not of much use without a receiver. To assure yourself of a receiver, you may have to use a little gentle persuasion to make your product of information seem desirable. Some healthcare professionals have difficulty understanding the subtleties of motivation. As an example, a diabetes educator, a dietitian, writes, "Type I patients not following their diets are required to have a blood glucose every month or I am not responsible for their nutrition management." (The threat is then repeated to Type II diabetics. "When they show me normal blood sugars and good weight control, *then* the procedure is liberalized. . . . We liber-

alize the rules every 3 or 4 months until *I feel confident* the person has learned to live with diabetes. Without routine visits and blood glucose analysis to *assess compliance*, I just listened to a *lot of excuses*." When you think of the patient as a consumer who seeks the advice and pays the bill, that's a lot like having your butcher tell you that you *will* buy a chicken. You will pan fry it, and bring him a notarized statement that shows you served it as he ordered . . . or else he will refuse to be your butcher, and no excuses.

Diabetes does not make a person subservient, nor a second-class citizen. It only means the person is a bit short on insulin. Tryanny is not a successful way to motivate anybody, and people with diabetes are just like anybody. There are some unbelievably rude, thoughtless, and hurtful remarks made to people with diabetes by caregivers, who are not basically rude and thoughtless people.

One example was a public meeting for about 150 people, most of whom had diabetes. A diabetologist, who certainly knew better, told the group, that "the District of Columbia has the highest incidence of fetal wastage in the country, and it's the diabetics who are the worst offenders." Can't you just see all those diabetic offenders, maliciously having dead babies just to skew the statistics and make D.C. look bad?

Second example: A young woman with diabetes learned she was pregnant. Her doctor referred her to a diabetes specialist. He examined her briefly and sat down at his desk to write orders. Without looking up he said, "You can have an abortion on Thursday, and I'll arrange for you to have your tubes tied at the same time."

In horror at this nightmare scene, she could only gasp, "Why?"

"Because you're a diabetic," he said. "You shouldn't have children, for their sake, as well as yours."

She fled the office, and when I saw her several days later, she was still understandably and unnecessarily upset.

Third example: A very responsible accountant, Type I diabetic, suffered from flu and was hospitalized with ketoacidosis. After seven days in the hospital, he was told by the resident, "You're self-destructive, just like all diabetics. The way you people abuse

yourselves, you might just as well commit suicide." The irony of that remark was that this careful and conscientious person was released from the hospital with a blood glucose level of 310 mg/dl. A week of the hospital's carefully monitored diet and insulin therapy had been no more successful in bringing the diabetes under control than had his own futile efforts.

In the hospital all but about 10% of the patients have unexplained blood glucose fluctuations, but in normal daily living we call this non-compliance. Actually, most patients are *not* out there wantonly "cheating." They want those normal blood sugars even more than you do. What they are doing is trying and failing, over and over again. It gets pretty discouraging, and what they need from you is to have you to be supportive and helpful, not critical and judgmental.

Hospitals may be a good place to find compliant patients, but at a heavy stress toll. In his normal life, the daily management of your patient's diabetes is more than just a dreary chore. He knows that what he does each day is to literally take his life in his hands. When he goes into the hospital, we suddenly take charge of his therapy, give him injections, test his blood and urine, regiment his diet, and moreover, cast a veil of professional secrecy over the lot. It becomes none of his business how much and what kind of insulin he is receiving, or what his blood sugar is. If he feels an insulin reaction pending, he can only ring his bell and hope he can persuade the nurse to provide a quick snack without waiting for a blood glucose.

It's no wonder the hospitalized diabetic lives in semi-panic. He feels that he has completely lost control. We can rationalize this stress by asserting that in the hospital, he is receiving the more valuable *professional* care. That just makes matters worse because diabetes is a do-it-yourself disease, and this implies that normally he is treated by an incompetent *amateur* — himself!

As diabetes educators we must never lose sight of the patient in the pursuit of our careers. The AADE Evaluation Manual<sup>2</sup> states under Compliance, "Compliance cannot always be inferred from a patient's verbal or written response." That is a euphemism for, "The patient is a liar." The Manual goes on to say, "Some

of the same information asked of patients can be asked of those individuals living with or caring for the diabetic. In fact, a simple but sound correlation study can be done by asking identical questions, and then comparing the responses.”<sup>2</sup>

I know how important evaluation is to your programs, but consider this: What in your life would justify a stranger (or even a friend) secretly asking your husband questions to see if she could catch you in a lie? That's a blatant invasion of privacy.

Whatever our needs as healthcare professionals, we must morally and ethically adhere to that beautiful line in the Hippocratic Oath that says, "First, do no harm." Moreover that must be interpreted to mean emotional as well as physical harm.

One of the final reasons for non-compliance is that it's just too expensive. Have you noticed what a growth industry diabetes has become? Diabetes education corporations are springing up everywhere. There are a lot of patient care "Cadillacs" for sticking fingers, giving injections, and measuring blood sugars. There are "gold plated," monogrammed insulin pumps and I hear that you can get a pancreas transplant for \$25,000 cash

with just an \$8,000 tip for the donor. The message is, that when you quit secreting insulin, you had better quickly start oozing money.

If we seriously want to be considered anything more professional than a trade association, we need to do some real soul searching to make sure we're not helping to *exploit* the diabetic patient. Sensitivity to human feelings is a gift I believe we all share, but sometimes, in a tough world, that sensitivity is like a muscle that doesn't get used. Try these simple exercises in your own practice:

1. Educate your patients, don't program them.
2. Listen as much as you talk and find out what it is that they want to learn.
3. Respect them as intelligent equals. Diabetes seldom affects the mind. (It's possible to do nuclear physics or play Chopin and still not quite understand carbohydrates.)
4. Teach your patients to be independent of you. Give them the tools they need and send them on their way. (You won't run out of work. Tragically, they're *not* an endangered species.)
5. Speak to them in their native tongue. (Save the jargon and med-

ical terminology for professional meetings.)

6. And when you speak of "control," be sure you mean control of the sugar, and not the patient.

It is easy for us to forget that bad control is the normal state for a person with diabetes. That is the definition of diabetes. Good control is an only occasionally successful achievement, a magnificent act of will. Never forget that diabetes is a miserable, chronic affliction that plagues, maims, and kills thousands including those we love. We're still a long way from bringing that destruction to a halt. Meanwhile, diabetes educators have stepped forward with skills and compassion to try and help. With that in mind, I'll conclude with a line from a prayer of my childhood. Perhaps we could adopt it for our motto:

"Make us ever mindful of the needs of others." □

Presented:  
American Association of Diabetes Educators  
Annual Meeting, San Antonio, Texas, 9/22/82

#### References

1. Advice from the dietitians, *The Diabetes Educator*, 1981, 7, 2, 43.
2. AADE Reference Manual for Evaluation of Diabetes Education Programs, 1982 p 13.

## NEW Products and Resources

This information is selected from descriptive material from the producers or manufacturers on the basis of usefulness and availability to readers. No endorsement is intended.

**Focus on Living, Focus on Family, and Self Blood Glucose Monitoring** are three new films produced by the same company as the popular *Focus on Feelings*. Emphasis is on the emotional effects of diabetes on peoples' lives. Most are 23 minutes long, available on 16mm or 3/4 video, for about \$415 (SBGM is \$270) or 3 day rental for \$60 from Oracle Film and Video, Venice, California.

**Three patient information booklets** have been recently published by Ames, on self blood monitoring, urine testing for sugar, and urine testing for ketones. They are readable, have helpful diagrams, in-

clude quizzes and case studies, and include a 30 day testing diary. The booklets are available, free, from Ames, PO Box 70, Elkhart, Indiana 46515.

**Clinical Diabetes** is a new publication of the American Diabetes Association. Geared for clinicians, it is available bimonthly in newsletter format for \$15/year. *Diabetes '83* is a new ADA newsletter, published bimonthly, for people who live with diabetes.

**Glukokey** is a new blood monitoring device with better than 97% accuracy. It uses rechargeable batteries, has a digital display, a 60 second timer for both blotting and readout, and can read any of three different test strips. Unlimited tests may be done without repeated calibrations. It is available for \$275 from Ulster Scientific, Inc., Route 9W North, Milton, NY 12547. Also Autolet is now available with a timer which starts automatically after the plunger is pushed.

**Accu-rynge** is a new lightweight (5 1/2 oz.) insulin pump. By turning separate sets of dials for basal and bolus the pump can be programmed with 99 choices of basal rate and 99 units for a bolus. A 3cc syringe stores U100 insulin. A beeper alarms if the

battery is low or the syringe empty. The pump, from Delta Medical Industries, costs about \$1500.

**Pump Pal 1** is a 6-oz. pump which can be worn under clothing. Although operated by batteries that provide the wearer with a constant infusion of insulin the bolus can be administered mechanically. With this feature the user can always operate the pump, even without batteries, and drain on the battery can be reduced. The pump comes with a harness that the user puts on before dressing. BioMedical Devices, Seattle, WA.

**Snap-Gauge** is a simple, take-home device for measuring penile rigidity. Instead of hospitalization for nocturnal tumescence tests to differentiate between physiological or psychological erectile dysfunction, this test can be taken at home. The velcro band's snap elements have three pre-set break-force constants for direct rigidity measurements, ranging from 90 to 160 mm Hg of intracorporal pressure. A patient may break none, one, two, or all three elements during a given night's test. Frequency cannot be measured. The band costs \$15-\$20 from Dacomed Corporation, 1701 E 79th St, Minneapolis, MN 55420.