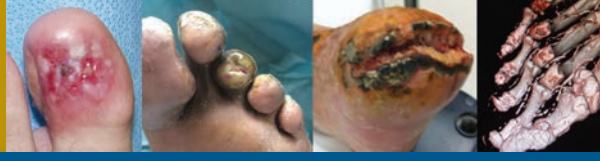

Doctoring Through the Complex Mindset of the Diabetic and Neuro-Insensitive Patient

It's all about understanding and compassion.

BY KENNETH B. REHM, DPM

It's an all too common scenario. A patient who has diabetes presents to the podiatrist's office for his/her routine visit. On previous visits, the importance of diabetic foot care and preventive principles was reinforced. You've instructed the patient to use diabetic foot conditioning cream for severely dry skin, and stressed the importance of diabetic shoes and corrective inserts, encouraging the patient to wear them as much as possible. You asked the patient to inspect his feet at least daily, and urged the patient to call you in-between visits if there are any new concerns or problems. Further, the patient was encouraged to maintain an appropriate exercise regime, to measure and control blood sugar, eat an appropriate diet, make appointments for routine medical checks with a diabetologist and/or primary care physician, eye specialist, and any medical providers recommended by the managing healthcare provider.

You, as the podiatric physician and surgeon, are unconditionally committed to preventing any of the secondary complications of this disease, especially as it applies to the lower extremity. Professionally, there aren't many things that would satisfy you more than to see one of your patients with diabetes come to the office with absolutely no avoidable complications; and that is your unreserved goal with all of your patients, all the time. The whole impetus for your practicing diabetic foot medicine is to permanently relieve all of these problems, prevent major amputations, and save limbs!

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Suddenly, reality insidiously sets in. This patient missed his last appointment and now shows up with a limb-threatening new problem. The callus under the first metatarsal is ulcerated with an extremely foul odor. It probes to bone. The patient noticed it a few days ago, but you know it has been there considerably longer. The patient didn't call right away, but got worried upon seeing pus this morning, and then called for an emergency appointment and demanded to be seen immediately.

Non-Compliance

When the patient is given the soonest appointment available, he arrives thirty minutes late. The initial interview reveals he did not wear his diabetic shoes and inserts as instructed, but he wore street shoes or dress shoes because he had some type of occasion to go to. He disclosed that his blood sugars have been extremely high, but he knew why. He has been eating foods he's not supposed to eat in spite of knowing that these foods are patently prohibited. He hasn't seen his primary care physician or endocrinologist lately and has not been taking his medications as directed.

Most podiatric physicians and surgeons, understandably so, would throw up their hands in exasperation. But is this non-compliance and non-adherence not part of the disease? Isn't this a part of the clinical profile that we healthcare providers should be able and willing to recognize and treat? Or do we turn a blind eye and blame the patient? Let's con-

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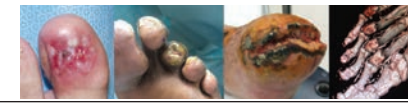

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sider that it is generally acknowledged that non-compliance/non-adherence rates for chronic illness regimens and for lifestyle changes can range from 50-70%. As a group, patients with diabetes are no exception, and are especially prone to substantial problems in this regard. This commonality and universality begs the questions: Why? And what can be done? To answer these fundamentally critical questions, let's take a closer look at these clearly complicated issues.

To begin with, patient non-adherence or non-compliance can take many forms. These can result from something very simple, such as the advice given to patients by their healthcare professionals being misunderstood, was carried out incorrectly, forgotten, or even completely ignored. Even challenges with hearing or different languages need to be considered. More complex and less transparent matters are better understood when the total individual patient situation is considered, especially in relation to the specific healthcare delivery system, reimbursement or insurance status, as well as the demographic, social, medical, mental, and psychological factors.

Compliance vs. Adherence

To delve further into this subject, it is important to differentiate between the concept of "compliance" and "adherence." Most healthcare providers use these two terms interchangeably, when it fact they have two distinct meanings. Compliance has been defined as "the extent to which a person's behavior coincides with medical advice." Non-compliance then essentially means that a patient disobeys the advice of a healthcare provider. Adherence, on the other hand, has been defined as the "active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result."

The two most common models of care implemented to treat and address the chronic healthcare needs of the person with diabetes are each individually based on either the concept of compliance or adherence. There are significant advantages and disadvantages to each.

First, there is the provider-directed model that can be thought of as the traditional approach, which centers on the patient-physician relationship. Patients who feel that their physicians communicate well with them and actively encourage them to be involved in their own care tend to more compliant. If a deep sense of trust is established in this relationship and patients believe that their physician is someone who can understand their unique patient experience, providing them with reliable and honest advice that is permeated with compassionate expression, then patient outcomes are greatly improved. On the other hand, if the patient-physician relationship is not optimal, patients can feel blamed for their non-compliance often being ascribed to negative personal qualities such as forgetfulness, lack of will power/discipline, or low level of education. This sets up a negative judgment toward the patient, leaving the patient totally out of the decision-making loop, perhaps avoiding possible negotiable compromises that might have improved the patient's participation in care. Concordance between physician and patient, restoration of mutual responsibilities and patient involvement in the decision loop are all vital to the success of the provider-directed model.

Secondly, there is the collaborative model of care.

In the care of acute healthcare conditions, provider-directed, compliance-oriented care may be very helpful. However, for treatment of chronic illnesses such as diabetes mellitus, this model of collaborative or co-managed care is more effective at setting goals and providing on-going support for optimal patient self-management behaviors over time, allowing patients to internalize these, making them a more permanent part of their health management construct.

Implicit in this concept is choice and mutual goal-setting, treatment planning, as well as implementation of the treatment regimen. The healthcare team is clearly identified, each are true partners in the outcome. Patients are encouraged to adhere to these mutually agreed-upon guidelines. In this approach, patients are taught to be fully responsible for diabetes self-management and in control of decision-making. Providers function in the background when it comes to the daily decisions that patients make to manage their diabetes, making them less dependent on their physicians and more dependent on their own knowledge base. Cooperation and respect are vital to cultivate the adult-to-adult relationship that promotes empowered patients and characterizes collaborative care of the patient with the health team. Provider advice, given in the context of this model, which recognizes the priority of patient decision-making, works very effectively in this set of patients with diabetes who suffer from loss of sensation in their limbs.

It is important to differentiate between the concept of "compliance" and "adherence."

Irrespective of what care model is used, there are many other factors related to patients' poor self-management of their condition. Demographic factors such as being an ethnic minority, in a low socioeconomic class and having a low level of education are strongly related to this issue. Belief systems, perceived seriousness of diabetes and its complications, psychological issues such as stress, mal-adaptive coping mechanisms, anxiety, depression, alcoholism, drug

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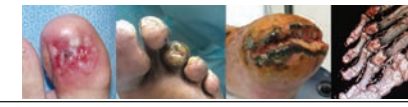

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abuse and dual diagnosis, put patients at risk for ignoring their recommended treatment regimens, poor engagement in their own care, and poor diabetes management.

Social issues play a pivotal role in the mindset of the insensate patient. Greater levels of social support, more family involvement, and closer relationships are associated with greater success in diabetes management, compliance, and adherence to the recommended regimen; and this serves to buffer the stress of the whole disease process. This is also true in cases where nurse case managers provide the social support.

Dr. Paul Brand

Dr. Paul Brand

Perhaps the most convincing discourse illuminating the psychological make-up that influences non-compliant and non-adherent behavior is brought forth by Dr. Paul Brand, who dedicated his life to research and treatment of the neuropathic and insensitive hand and foot in diabetes and leprosy. He was a pioneer in the psychology, techniques and treatment regimens we use today to deal with the problems associated with these conditions. He described people coming to his leprosy clinic in India who were running barefoot with deep, infected, and open ulcers on the bottoms of their feet, throwing their crutches away, merely to have a chance at being seen and treated by the visiting medical practitioners who came to their village only very rarely. Dr. Brand describes their running so hard and for such a distance that their tibia became disconnected from the foot which became entrenched with the gravel from the surface they were running on, as if they were not aware and did not care about their diseased foot. They were not and they did not, but that's only the surface of the story!

In diabetes and in leprosy, people lose their instruments of sensation and, therefore, its connections to the brain. If nothing comes from the brain, the brain shuts down. Our life is in the brain and our brain is informed by our senses. We are flooded with information from the senses all the time. According to Dr. Brand, this is the pillar of life, without which life becomes meaningless. We are therefore dependent entirely on our senses. Because life is in the brain and not in the hands or feet, if we are not informed of something through our senses, to us that thing does not exist. Accordingly, if we do not feel our feet, because of this insensate nature, those feet do not exist in our minds, and then we do not bother to take care of them. This is the crux of the reason, according to Dr. Brand, that the diabetic patient with loss of sensation appears non-compliant and non-adherent.

Loss of Touch Sensation

Further, touch is our most important validating sense, the sense that ensures us that things are real. We learn to trust our eyes only when we validate what we see with other senses, especially with touch. What we trust more than anything else is touch because touch means you have made contact with that something. Touch makes it real, and therefore, according to experts, is more fundamental than sight. Consequently, if we see something, but cannot validate that, we feel deceived; and once we are deceived, our life changes. Hence the non-compliant and non-adherent behavior ascribed to the person who has diabetes with a threshold loss of sensation.

In amputations, people trust their phantom feeling and body image more than they trust what they see. The most profound deception in the world is when this touch is deceived. Those who have diabetes with peripheral neuropathy and a fully developed insensitive foot are actually experiencing what providers for patients who suffer from insensitive feet call reverse phantom syndrome.

When asked to draw themselves, people with insensitive feet will invariably draw themselves without a foot.

That person does have a foot; but there is no body image, as expressed through touch, to confirm and reinforce that. They admit they have a useful instrument to walk on, but it doesn't feel like the feet are actually part of them.

It is interesting to note that when asked to draw themselves, people with insensitive feet will invariably draw themselves without a foot. In the minds of these people, they do not have a foot. In fact, there are research studies, as described by Dr. Brand, that demonstrate that rats who do not have sensation in their feet will eat them, as they would any other extraneous piece of meat.

Another root of non-compliant, non-adherent behavior in those with insensitive limbs, according to Dr. Brand, stems from when they're adversely affected by the negative regard in which they perceive other people treating them. The insensate person senses disgust in others' faces when these people look at their ulcerated feet. Subsequently, this makes the insensate people feel that they're offensive in some way. People then become ashamed of their ulcerated feet, even after the wounds have healed, not only because of the factors previously discussed surrounding loss of sensation, but also for the reason that other people have now regarded the person's insensitive feet as being presumably dead disgusting tissue. And so, just as the person himself has a body image that denies the foot, the perception is that other people have developed the same image as well.

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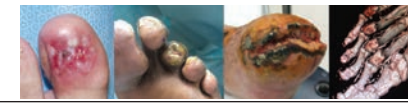

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It's easy to see how this reinforces the adversative behavior.

Moreover, when a healthcare professional, unfamiliar and untrained in the management of the insensitive patient, sees how this person treats his own feet, the practitioner then would look askance at this person with disdain, as being complacent, ignorant, and uncaring about life and limb. Dr. Brand speaks of the person who suffers from a limb-threatening foot ulcer to whom he has painstaking applied a series of plaster casts to offload an unrelenting ulcer. When the wound is finally and totally healed, he instructs the patient, in no uncertain terms, stressing time and time again, the absolute importance of wearing appropriate proper-fitting shoes, and avoiding going barefoot to prevent another ulcer and risk possible loss of limb. He custom-makes expensive prescription shoes for the patient and conscientiously educates him on their use as well as any other preventive measures. All this, only to bump in to the patient on the street wearing tight, pointed or high heeled shoes.

The most salient feature of the doctor-patient relationship must be that the doctor must tune in to the mind of the patient.

With his characteristic intuitive instincts, Dr. Brand encourages the healthcare professional to look at this person from another point of view. He specifies that the insensitive patient is task-oriented. For instance, if patients want to go to a party wearing pointed or high-heel shoes, then that's what they want to do regardless of the effect it has on their feet. Remember, their feet are not real to them. On the other hand, those with no loss of sensation in the limbs are body-oriented. Every part of the body, especially the limbs, is real to them; and the body, then, naturally becomes the center of perception of themselves, and therefore factors into every decision that is made regarding their health.

Therefore, the heart of the compliance and adherence problems with the insensitive person, according to Dr. Brand, is that they do not regard their (perceived to be disgusting) foot as being really part of themselves. He states emphatically that the healthcare provider for these patients has the power to reverse the course of this unhealthful, self-destructive pathological pattern, and is indeed obligated to do so.

The physician must be willing and able to positively influence the mental state of their patients.

A Solution Pathway

Dr. Brand offers a solution pathway. In addition to all the good medical attention that is expected from any healthcare provider who's committed to quality care, such as appropriate education and counseling, encouraging optimum medical care, good shoes and inserts, a healthful diet, blood sugar control, exercise, etc., this healthcare professional must focus on his and the patient's attitude and perceptions. The most salient feature of the doctor-patient relationship must be that the doctor must tune in to the mind of the patient. Doing this requires showing absolute respect for the patient, and being able to demonstrate that in a rather vociferous way. He advocates the provider making it obvious that he knows how good the foot still is, even though the patient doesn't think so. It is important to show that there is still a healthy part of the foot, and this part is precious and wonderful.

He recommends the provider never examine the foot without finding something to praise and show appreciation for, telling patients things such as: "Look at how your wound is healing and how wonderful it is that your body has the power to do that." Demonstrate to the patient that the foot is real by touching it and pointing out things such as, even though they may have lost some nerves, they still have blood vessels that provide the ability to heal. Show them the healing cells and emphasize that the body is working well in order to produce them. Point out that it's still a good functional foot, and that it will last for years to come.

One major point Dr. Brand emphasizes is that people who are healing need to feel that they're not alone in their disease. Someone is in on this mission with them and cares about the outcome as if they were close family. That is exactly why, as research shows, that people with a close family structure and support do much better in the healing arena.

Dr. Brand goes on to say, "You can feel pain for them even though they don't feel pain themselves, and you can show distress for them like you are in partnership with them, as we're working on our foot together."

Conclusion

In summary, our search just touched the surface of the answer to the question, "when we know what is good for us, why do we not do it?" Also, we've attempted to answer the question, "what can be done to improve patient engagement in the subset of people who have diabetes who have insensitive limbs?" There are many external causes we can point our fingers at, but perhaps these are peripheral to the fundamental core of the problem. No matter what literature was reviewed to prepare for

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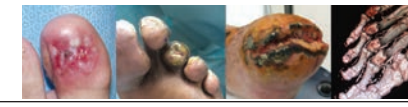

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this dialogue, the central issue boiled down to the mindset of the patient.

The physician must be willing and able to positively influence the mental state of their patients. The context in which the patient is seen and treated is a major contributor to the positive outlook aspired to, and should not be considered trivial. Such things as having a helpful, friendly, and giving staff, getting to know patients, creating less anxiety-provoking encounters, and initiating humor when appropriate into the clinical mix are essential elements to any successful medical setting. Efficacious physician communication tends to motivate patients to comply and adhere. Perhaps the most important element in the successful role of the physician is to create a trusting bond with the patient. This connection is essential to the emotional disclosure of the patient and a crucial component of the physician-patient relationship. This concordant relationship is the key to greater patient involvement. There is no question that managing the diabetic and neuro-insensitive patient can be frustrating to all providers involved, but it is imperative that we, who deal with patients who have diabetes and insensitive limbs, are aware of how nurturing attitudes and relationships can be determinant factors in the successful management of these patients, without which effective care is undermined.

Perhaps the most important element in the successful role of the physician is to create a trusting bond with the patient.

To quote Dr. Brand one more time, "we are not treating foot problems… we are treating people who have foot problems." Once we have made this paradigm shift, our patients will be the recipients and will accomplish what they need to. At this point they are saved for life… and so will be their legs. **PM**

Dr. Rehm is Medical Director, The Diabetic Foot & Wound Treatment Centers San Marcos, California. He is Board certified by the American Board of Multiple Specialties in Podiatry.