

## Encouraging Effective Self-management in Diabetes

an interview with

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DOI: 10.17925/USE.2006.00.1.28

Many patients with diabetes do not follow, or are unable to follow, provider recommendations for self-management as closely as is needed. This is often due to feeling overwhelmed, confused, or discouraged by the 'job' of diabetes. These patients may be young or old, male or female, or have type 1, type 2 or gestational diabetes.

From the patient's perspective, living with diabetes can be a tough, demanding, and frustrating job from which there are no vacations. Effective self-care requires a significant amount of effort and vigilance every day. Recommendations to make healthy food choices and to exercise regularly may require major, difficult changes in daily habits. Insulin and/or oral hypoglycemic agents—and, in many cases, a slew of other medications—must be remembered and used appropriately. Blood glucose levels need to be checked regularly, feet should be checked daily, supplies must be purchased at regular intervals, and all self-care actions must be kept in a reasonable equilibrium so as to avoid hyperglycemia and hypoglycemia. Proper attention to managing blood pressure and lipid levels is also critically important.

When patients are unable to cope effectively in response to the many demands of diabetes, they are often labelled as non-compliant, unmotivated or 'in denial'. In fact, such labels are almost always inaccurate. This misconception needs to be corrected if things are to improve.

Almost all patient with diabetes would prefer to live a long, healthy life. Typically, they are not unmotivated to do so. Instead, the problem is that they are struggling with a series of personal obstacles. The key to promoting self-management is to help patients identify and overcome these obstacles.

The critical obstacle concerns the issue of perceived importance. Many patients have come to believe that diabetes self-management is simply not worth the effort. There are a number of reasons why patients come to this belief. One of the most common is the pernicious influence of a depressive disorder. In the

presence of depression it is not uncommon to believe that nothing is worth the effort. Accumulating evidence indicates that depression is common in diabetes. People with diabetes are 1.5 to two times as likely to have a depressive disorder compared with people who do not have diabetes.

Depression in diabetes has been linked to impaired self-management, poorer glycemic control, increased rates of hospitalisation, higher risk for microvascular and macrovascular complications and increased mortality.

A study published in the June 2005 issue of the American Diabetes Association (ADA) journal, *Diabetes Care*, examined the long-term effects of diabetes and depression on mortality. The results showed that, whether a person had diabetes or not, depression raised the risk of mortality over the eight-year period. Diabetes, whether the person were depressed or not, also raised the risk of mortality. Most importantly, it was the combination of depression and diabetes that raised the risk the most. People who had diabetes and were significantly depressed were 2.5 times more likely to die over the eight-year period compared with people who had neither condition. Comparing people with diabetes who were depressed versus people with diabetes who were not depressed, the researchers reported that depression increased the risk of mortality by 30%.

The good news is that standard treatments for depression, including antidepressant medications and certain forms of brief counseling, have been shown to be effective in helping people with diabetes to recover from depression. It seems likely that such treatments, especially if they also address people's negative feelings about diabetes, could also help people to manage their diabetes more effectively and improve their health over the long term.

However, it is difficult to demonstrate this benefit, as concluded in the IMPACT study in the June 2004 issue of *Annals of Internal Medicine*. One of its objectives was to determine whether enhanced care for depression would improve glycemic outcomes in

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<sup>1</sup> Diabetes Control and Complications Trial (DCCT) Research Group, *N Engl J Med* (1993).

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<sup>3</sup> Koubek, R.J. The Role of Lancet Device Design in Pain Experienced During Self-Testing of Glucose; Fruhstorfer, H. Virtually Pain-Free Collection of Blood from the Finger Pad. Data on file.



older adults with diabetes and depression. While a significant, positive impact on depression was demonstrated, glycemic control did not improve. However, mean glycemic control at baseline was already quite good (7.1%), which may explain why the intervention was unable to influence glycemic control.

The message here is that, while physicians may not have the time to talk at length to their patients about issues seemingly outside of diabetes, taking the time to identify and treat depression may be critical for long-term success.

Another study published in the October 2005 issue of *Diabetic Medicine* examined the emotional concerns and self-management behaviours of 5,104 adults with type 1 and type 2 diabetes from 13 countries around the world, including the US, France, Germany, Japan,

Providers agreed that psychological concerns were common in their patients and that these problems contributed to poor diabetes self-management. Unfortunately, less than half of the providers felt able to identify and address the psychological needs of their patients.

Another reason why patients may come to believe that diabetes self-management is simply not worth the effort is that they do not see the benefit of their actions. They may undertake an exercise or nutritional programme and not see a corresponding improvement in their blood glucose levels and therefore become discouraged.

Patients may also feel that the cost of effective self-care is too high. This could be a literal cost, i.e. the cost of medications or healthy food, but could also be a cost to their lifestyle.

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Australia, and India. The beliefs and attitudes of 2,705 physicians and 1,122 nurses from those same countries were also investigated.

While there was a great deal of variability from country to country, the researchers found that the majority of patients in almost all countries did not believe they were succeeding with their diabetes self-management. This was especially notable in the areas of diet and exercise, where less than 40% of patients believed they were 'completely successful'.

In general, healthcare providers were even more pessimistic, believing that their patients were less successful with diabetes self-management than the patients reported.

A majority of patients reported a host of diabetes-related worries, including fears about the disease getting worse, feeling alone with diabetes, feeling concerned that diabetes will make it difficult for them to care for their families in the future, and feeling worried about hypoglycemia. More than 40% of patients with diabetes worldwide reported poor psychological well-being.

When people with diabetes come up against these barriers, they struggle with effective self-care. They feel that what they are being asked to do is not achievable or realistic. Patients often perceive self-care recommendations from their healthcare providers as overly complicated, confusing and—on occasion—meaningless.

There are no ironclad guarantees of metabolic success in the short-term nor prevention of microvascular and macrovascular complications in the long-term. These patients start to believe that the effort required to manage diabetes successfully is just too much, the work is too difficult or too confusing, and/or the results are too unrewarding.

The patient may develop a fatalistic attitude, feeling overwhelmed and defeated by diabetes and the associated responsibilities of diabetes self-care, and come to the belief that having diabetes is a death sentence. The patient may have feelings of anger about diabetes, frustration with the regimen, fear about the possibility of long-term complications, guilt about one's own poor self-care, and/or a more pervasive depression may be apparent.

Feeling defeated, the patient may decide to partially or fully ‘quit’ his diabetes, thinking about diabetes as little as possible and significantly reducing their involvement in their own diabetes care. The major consequence, of course, is chronically elevated blood glucose levels. To avoid the fear and guilt which often accompany such actions, the patient is especially likely to avoid any diabetes-related tasks which may give them feedback about the consequences of their poor self-care (e.g. blood glucose testing or physician visits). They may also strive to hide their diabetes and/or their worries about diabetes from others.

What can be done for the patients who have given up self-management and are suffering from ‘diabetes burnout’? Many patients may be uncomfortable talking about their diabetes frustrations with their healthcare provider or have difficulty recognising their own complex feelings about diabetes.

respectful of patient’s negative feelings about diabetes.

The development of a collaborative relationship takes time, so continuity of regular care and contact is critical. If at all possible, patient and provider should schedule a series of regular visits over six to 12 months, encouraging the patient to attend these visits, regardless of his success at self-care.

In this manner, the patient is more likely to perceive that his relationship with his provider is on-going, and to feel cared for and valued.

Self-care goals that are vague or too unrealistic or if the patient is not certain how they can be implemented are not helpful. The patient, for example, who believes that the only reasonable self-care target is to ‘do everything and do it perfectly’ is doomed to fail. To avoid this problem, healthcare providers should help patients to

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To overcome this, physicians should consider simple ways to encourage greater openness during patient interviews. For example, rather than asking: “You’re not having any problems with managing your diabetes, are you?”, they might consider saying: “Everyone struggles with managing their diabetes from time to time. Can you tell me one or two things about diabetes that you find tough?”

By normalising the aggravation and distress that often accompany diabetes self-care, patients are more likely to feel at ease about discussing their own feelings.

As a part of the negative relationship with diabetes, patients often expect or experience a similarly negative relationship with their healthcare providers. In particular, they may fear that as a consequence of their struggle with diabetes self-care they will be judged, humiliated, or treated in a patronising manner. Consequently, they may be withdrawn during medical visits, or may tend to cancel or postpone appointments.

To enhance the patient-provider relationship, it is critical that healthcare providers be empathetic and

construct self-care goals that are concrete, specific, time-limited, uncomplicated, measurable, achievable, and, most importantly, personally meaningful for the patient.

An overly authoritarian approach should be avoided and the provider should emphasize flexibility, creativity, and the patient’s own control in goal setting. The focus must be on the collaborative negotiation of goals for specific self-care behaviors, focusing primarily on behavioral rather than numerical outcomes.

For many patients, living with diabetes is hard work. Feelings of frustration and distress are not uncommon. However, it is crucial to bear in mind that most patients with diabetes want to live a long and healthy life.

However, some may be experiencing barriers to effective self-care and spending time on finding out what these barriers are and negotiating means to overcome them will pay dividends to both the provider and the patient in the long term. ■

*This article has been adapted from an interview given by Dr Polonsky to US Endocrine Disease 2006.*