Diabetes is a challenging disease to manage successfully. Although the care regimen is complex, patients with good diabetes self-care behaviors can attain excellent glycemic control. However, many patients do not achieve good glycemic control and continue to suffer health problems as a result. Diabetes health care providers know that if only their patients adhered to their treatment recommendations, they could do well and avoid diabetes-related complications. The fact that so many patients do not can be very frustrating.

This article reviews studies documenting the extent of and factors related to adherence problems among patients with diabetes. Recommendations are made for improving patient adherence, with an emphasis on adopting a collaborative model of care and skillful use of behavioral change strategies.

Scope of the Problem
It has been generally acknowledged for years that nonadherence rates for chronic illness regimens and for lifestyle changes are ~ 50%. As a group, patients with diabetes are especially prone to substantial regimen adherence problems. In general, research has shown that the diabetes regimen is multidimensional, and adherence to one regimen component may be unrelated to adherence in other regimen areas. For example, research has shown better adherence for medication use than for lifestyle change. In other studies, adherence rates of 65% were reported for diet but only 19% for exercise. Two studies showed that adherence to oral medications in patients with type 2 diabetes was 53 and 67% when measured by electronic monitoring. In a more recent study of older type 2 diabetic patients’ adherence to sulfonylureas, adherence, when measured by pill counts, was 104% to a one-per-day regimen and 87% to twice- or thrice-daily regimens. However, electronic monitoring revealed reduced adherence rates of 94 and 57% for once-daily and twice- or thrice-daily regimens, respectively. Self-monitoring of blood glucose (SMBG) has been used for > 25 years, with recent technological advances making the procedure very easy to use. Research has shown that increased SMBG is associated with improved glycemic control.

Despite the improved technology, however, patients often do not adhere well to this aspect of the diabetes regimen. A recent study using a large national sample of patients with type 2 diabetes found that 24% of insulin-treated patients, 65% of those on oral medications, and 80% of those treated by diet and exercise alone either never performed SMBG or did so less than once per month. Daily SMBG (at least one blood glucose check per day) was reported by only 39% of patients treated with insulin and just 5% of those treated with either oral medications or diet and exercise.

The findings from the recently published Cross-National Diabetes Attitudes, Wishes, and Needs (DAWN) Study showed patient-reported adherence rates for medication in type 1 and type 2 diabetic patients of 83 and 78%, respectively; SMBG adherence was 70 and 64%, respectively; and appointment keeping adherence was 71 and 72%, respectively. The adherence rates observed for diet for type 1 and type 2 diabetic patients were 39 and 37%, respectively, and for exercise they were 37 and 35%, respectively. Providers reported significantly better adherence for type 1 than for type 2 diabetic patients across most regimen domains.

Factors Related to Adherence
To improve patient adherence, it is important to understand why nonadherence occurs. A substantial literature has documented a number of factors related to diabetes regimen adherence problems. It is helpful to consider demographic, psychological, and social factors, as well as health care provider, medical system, and disease- and treatment-related factors.
Demographic factors
Demographic factors such as ethnic minority, low socioeconomic status, and low levels of education have been associated with lower regimen adherence and greater diabetes-related morbidity. For example, lower rates of SMBG have been observed among minority African-American and Mexican-American patients.

Psychological factors
Psychological factors are also linked with regimen adherence. Appropriate health beliefs, such as perceived seriousness of diabetes, vulnerability to complications, and the efficacy of treatment, can predict better adherence. Patients adhere well when the treatment regimen makes sense to them, when they believe the benefits exceed the costs, when they feel they have the ability to succeed at the regimen, and when their environment supports regimen-related behaviors. There is no evidence of adherence being associated with any particular personality styles.

Higher levels of stress and maladaptive coping have been associated with more adherence problems. Psychological problems such as anxiety, depression, and eating disorders have also been linked with worse diabetes management in both youths and adults with diabetes. The recent DAWN study showed that a significant number of diabetic patients have poor psychological well-being and that providers reported that these psychological problems adversely affected regimen adherence. This study also showed that many health care providers do not feel confident in their ability to identify psychological problems in their patients or to provide the psychological support their patients need.

Social factors
Family relationships play an important role in diabetes management. Studies have shown that low levels of conflict, high levels of cohesion and organization, and good communication patterns are associated with better regimen adherence. Greater levels of social support, particularly diabetes-related support from spouses and other family members, are associated with better regimen adherence. Social support also serves to buffer the adverse effect of stress on diabetes management.

Health care provider and medical system factors
Social support provided by nurse case managers has been shown to promote adherence of diabetic patients to diet, medications, SMBG, and weight loss. Another study showed that having regular, frequent contact with patients by telephone promoted regimen adherence and achieved improvements in glycemic control, as well as in lipid and blood pressure levels. It was observed in the Diabetes Control and Complications Trial that one of the key elements to success in achieving good glycemic control was the availability of support provided to patients by the health care team.

In addition to ability to obtain support from health care team members, the quality of the patient-doctor relationship is a very important determinant of regimen adherence. Research has demonstrated that patients who are satisfied with their relationship with their health care providers have better adherence to diabetes regimens. In addition, patients who have a “dismissing attachment” style (discomfort trusting others [negative view of others] and therefore greater self-reliance [positive view of self]) toward their doctor and who rate their patient-provider communication as poor have been shown to have lower adherence rates to oral medications and SMBG. Organizational factors that promote adherence include reminder post cards and phone calls about upcoming patient appointments and appointments that begin on time.

Disease- and treatment-related factors
Research has generally shown that lower regimen adherence can be expected when a health condition is chronic, when the course of symptoms varies or when symptoms are not apparent, when a regimen is more complex, and when a treatment regimen requires lifestyle changes. Studies with diabetic patients indicate better adherence to medications than to prescribed lifestyle changes and better adherence to simpler regimens than to more complex ones.

Compliance and Adherence
Most health care providers use the term “compliance” instead of “adherence,” although these concepts are quite different. Compliance has been defined as “the extent to which a person’s behavior coincides with medical advice.” Noncompliance then essentially means that patients disobey the advice of their health care providers. Patient noncompliance is attributed to personal qualities of the patients, such as forgetfulness, lack of will power or discipline, or low level of education. The concept of noncompliance not only assumes a negative attitude toward patients, but also places patients in a passive, unequal role in relationship to their care providers.

Adherence 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.” Implicit in the concept of adherence is choice and mutuality in goal setting, treatment planning, and implementation of the regimen. Patients internalize treatment recommendations and then either adhere to these internal guidelines or do not adhere.

However, the concept of adherence has been criticized because of its focus on patients and because of the nature of the diabetes regimen itself, which is dynamic rather than static. Furthermore, it is not useful to think of adherence as a unitary construct, but rather one which is multidimensional, because patients may adhere well to one aspect of the regimen but not to...
Continued from p. 72

others. Another way to conceptualize patient behavior related to diabetes management is to use terms such as “self-care behaviors” or “self-management,” which simply describe the behaviors patients engage in to manage their health condition.

Collaborative Care Model for Chronic Illness

In the care of acute health conditions, provider-directed, compliance-oriented care may be very helpful. However, for treatment of chronic illnesses such as diabetes, there are clear limitations to compliance- or adherence-oriented approaches. Diabetes is essentially a self-managed disease and therefore requires patients to have a degree of autonomy motivation to successfully perform optimal self-management. In this model, health care providers can provide autonomy support to their patients to enhance their success at disease management behaviors.26 From the perspective of the health care delivery system, this model of collaborative or comanaged care emphasizes providers setting goals with their patients and providing ongoing support for optimal patient self-management behaviors over time.27,28

This model has been very well articulated in the empowerment approach to diabetes management.29,30 In this approach, patients are recognized as being fully responsible for diabetes self-management and in control of decision making; providers are not in control of the many daily decisions that patients make to manage diabetes. Cooperation and respect are necessary in the adult-to-adult relationship that characterizes collaborative care with empowered patients. This does not mean that provider advice should not be provided for optimal diabetes care. In fact, provider advice can be helpful in improving diabetic patients’ behaviors, such as medication taking and weight loss efforts.31 However, to be most effective, provider advice should be given in the context of the collaborative care model, which recognizes the primacy of patient decision making.

Improving Patient Self-Care Behaviors

Ironically, to improve diabetic patients’ compliance or adherence, health care professionals should first abandon the concept of trying to get their patients to comply or adhere better.32 This requires an attitude shift in recognition of patient responsibility for diabetes self-management, as well as a new type of collaborative relationship with patients. There is no question that diabetes management can be frustrating for health care providers, but it is important to be aware of how these attitudes may determine approaches to clinical practice and undermine effective diabetes management.33

Traditional approach to health behavior change

In the traditional approach to health behavior change, the health care provider is seen as the expert who knows what is best for the patient; advice-giving is the technique used for the delivery of knowledge to the patient.34 This assumes that patients should change their behavior, want to change, and that their health and their prescribed regimen are major priorities for them. However, giving advice may not be the most skillful approach to health behavior change because telling patients what to do undermines their sense of autonomy, generates resistance, may not consider what is important to patients, and does not work in the majority of cases.

To ensure that behavior change does not occur, the following techniques would be helpful: do not establish rapport; tell patients what to do; take control away from patients; misjudge patients’ sense of the importance of behavior change and their confidence in achieving change; overestimate their readiness to change; argue with patients; blame them for not taking better care of themselves; and use scare tactics.

Assessment of diabetes management problems

Effective behavioral interventions first require an understanding of why, how, and when patients do not engage in optimal diabetes self-management behaviors. Assessment of the reasons for lack of optimal self-care is important before embarking on specific behavioral interventions that may fail if specific regimen barriers are not understood and dealt with as part of the intervention. Disease-related knowledge and skills may be lacking, or patients may have inappropriate health beliefs and attitudes. Specific environmental barriers may adversely affect patients’ ability to perform appropriate self-care. Patients may be socially isolated or have conflicted family relationships that undermine diabetes management. There may be specific psychological or psychiatric disorders, such as depression, anxiety, or eating disorders, that impair effective diabetes management.

These issues should be screened for their potential role in diabetes management problems, and more comprehensive assessment should be conducted as needed by other members of the health care team, including diabetes educators and behavioral specialists, such as social workers, psychologists, and psychiatrists. Appropriate therapies, such as stress management, cognitive behavioral therapy, or psychotropic medications, may then be provided as clinically indicated.

Effective behavioral interventions

Health care providers must understand behavior change as part of an interpersonal process. Although patients are responsible for their own decisions and self-care behaviors, patient outcomes are also affected by health care provider behaviors. To be most effective at health behavior change, health care providers should have a patient-centered approach, cultivate a collaborative relationship, communicate clearly, and provide directives (advice) when patients are ready to hear and learn more about the new recommendations.30,34
Several specific strategies can help patients with behavior change. First is the establishment of rapport, conveying genuine interest in patients. An agenda should be set in terms of talking about some specific health care goals. Providers should assess the importance patients place on and the confidence they feel with respect to specific health behaviors to determine their readiness or motivation. It is important during the clinical encounter to explore the importance of regimen-related behaviors and build patient confidence. Assuming that patients do want to hear what providers want to tell them, exchanging information is a critical part of the behavior-change process. A rationale should be provided for the recommended treatments. However, it is important to remember that simply providing information to increase knowledge will not guarantee that behavior change occurs.

Providers face several challenges. The first is simply to listen to their patients and find out what is important to them. This may be difficult to do in a busy clinical setting, but even a few minutes of asking and listening goes a long way in establishing and maintaining rapport. It is also a challenge to achieve congruence with patients’ readiness to change. Reducing patient resistance to change is another challenge. Effective ways to reduce resistance include emphasizing personal choice and control; reassessing patients’ readiness, beliefs about importance, or confidence; and sometimes backing off and joining with patients in their decisions.

In effective behavioral consultation, providers encourage patients to express their concerns and use active listening techniques, such as open-ended questions, clarifications, reflective statements, and summary statements. Health care providers help their patients to be more active, brainstorm options, and sometimes backing off and joining with patients in their decisions.

In effective consultation, providers encourage patients to express their concerns and use active listening techniques, such as open-ended questions, clarifications, reflective statements, and summary statements. Health care providers help their patients to be more active, brainstorm options, and sometimes backing off and joining with patients in their decisions.

Several specific behavioral strategies and psychosocial interventions can be employed to improve patient self-care behaviors once it is established that patients want to work on particular goals. Self-monitoring is an integral component of behavior change, serving to heighten awareness of the behavior, understand its determinants, and track progress over time. It is helpful to gradually implement new regimen-related behaviors over time, especially for more complex regimens. Goal setting is important to achieving success at behavior change, and goals should be specific and easily measured.

It is particularly important to assess and program social reinforcement and support for new behaviors, not only in patients’ home environment, but also in the medical office as part of the clinical encounter. Sometimes it is useful to have formal behavioral contracts that specify treatment goals and program positive outcomes for patients contingent on them meeting their goals. Another effective strategy is problem solving, which teaches patients how to identify problems, generate possible solutions, make a reasoned decision about a solution, and then evaluate the success of that choice. Providing written instructions for new regimen prescriptions is helpful because patients may not remember all the details discussed during the clinical encounter. It is also important to recognize the limits of one’s ability to change patient behavior. Sometimes it is best to refer difficult or complicated cases to behavioral health specialists who have the training and time necessary to intervene more effectively.

Summary

Compliance or adherence problems are common in diabetes management. Many factors are potentially related to these problems, including demographic, psychological, social, health care provider and medical system, and disease- and treatment-related factors. The terms “compliance” and “adherence” are problematic constructs that may actually serve to perpetuate diabetes management difficulties.

Because diabetes is a chronic illness requiring a variety of self-management behaviors, a patient-centered collaborative model of care recognizing patient autonomy provides a more skillful approach to improving diabetes self-care behaviors. To improve patients’ diabetes self-management behaviors, health care providers should cultivate patient-centered relationships that respect patient autonomy; organize their clinic or office to be patient-friendly; provide continuity of care with interim telephone contacts; talk collaboratively with patients about treatment rationales and goals; brainstorm and problem-solve with their patients; gradually implement and tailor the regimen; provide written instructions; use self-monitoring, social support and reinforcement, and behavioral contracts; and routinely refer patients to behavioral health specialists.

REFERENCES


25Glasgow RE, Anderson RM: In diabetes care, moving from compliance to adherence is not enough. Diabetes Care 22:2090–2092, 1999


Alan M. Delamater, PhD, ABPP, is director of clinical psychology in the Department of Pediatrics and a professor of pediatrics and psychology at the University of Miami School of Medicine in Florida. He is an associate editor of Clinical Diabetes.