

Changing Behavior

Practical lessons from the Diabetes Control and Complications Trial

RODNEY A. LORENZ, MD
JEANNE BUBB, MSW
DIANNE DAVIS, BS
ALAN JACOBSON, MD

KARL JANNASCH, PHD
JOHN KRAMER, PHD
JANIE LIPPS, MSN
DAVID SCHLUNDT, PHD

The recently completed Diabetes Control and Complications Trial (DCCT) has elicited renewed interest in behavior change strategies, because intensive therapy of IDDM in the DCCT was a comprehensive behavioral change program with unequivocal health benefits (1,2). Intensive therapy lowered blood glucose levels and slowed the appearance and progression of microvascular and neuropathic complications because participants changed many behaviors, including testing blood glucose and administering insulin more frequently, quantifying and regulating dietary intake, and modifying diet, insulin, and physical activity to balance their effects on blood glucose levels. It is natural to ask what can be learned from the DCCT about changing behavior that is pertinent to diabetes management in clinical practice.

The DCCT compared two treatment programs that differed in many ways. Among the differences between the two treatments was the more frequent use of behavioral change strategies in the intensive therapy group. Use of specific behavior change strategies depended on the needs of individual patients. In addition, while the framework of intensive therapy was dictated by the study protocol, the detailed application of behavioral change strategies is presumed to have varied with the skills and preferences of each Clinical Center staff, as was also true of other elements of treatment such as insulin man-

agement and the choice of pump or multiple injection therapy. Consequently, there were uncontrolled differences across clinics and individuals in the use of behavioral interventions. Therefore, the DCCT Study Group has not attempted to draw systematic conclusions about the effectiveness of specific behavioral change strategies or other elements of the intensive therapy program. Nevertheless, it is possible to offer opinions on the behavioral strategies that seemed most helpful. To generate a broad synthesis of practical lessons from the DCCT, the first author recruited collaborators from several DCCT Clinics and disciplines, including nursing, nutrition, clinical psychology, psychiatry, and social work. The practical lessons we offer here were not discovered or used for the first time in the DCCT, but are well grounded in a large body of literature, examples of which we cite. A short list of additional reading is also included. The point emphasized here is that the DCCT has demonstrated that these strategies are truly effective in achieving long-term behavioral changes and health benefits in subjects with IDDM.

Before discussing specific behavioral change strategies, we wish to articulate a general principle suggested by the DCCT: ordinary people can adopt and maintain substantial behavioral changes. Because of the extraordinary adherence of the DCCT volunteers to the protocol, it has been implied that they were so well

motivated that their experience cannot be generalized to most patients. It is true that the DCCT volunteers were highly selected: 1,441 were randomly selected from nearly 7,000 potential volunteers who made initial contact with the DCCT clinics, and an unknown fraction of these removed themselves from the recruitment process or were excluded because of adherence concerns (3). The screening process included a 2-week simulation of intensive therapy, an informed consent process designed to fully disclose the demands of intensive therapy, and judgments about the volunteers' potential adherence. All these procedures were intended to help select the subjects most likely to adhere to the protocol.

Nevertheless, we believe it is erroneous to suggest that the patients were too highly screened to extrapolate their experience to others. Many potential volunteers were excluded by eligibility criteria unrelated to adherence issues, such as mild degrees of hypercholesterolemia, residual C-peptide secretion, or absence of retinopathy in those with >5 years duration of diabetes. Some observers may have assumed that each DCCT Clinic selected the few best patients from existing clinical cohorts. In fact, most of the volunteers had not been seen in the DCCT Centers before recruitment visits. Many were not regularly engaged with any source of diabetes care before the DCCT and acknowledged that their own self-care was inadequate before entering the study. Although they were judged to be capable of practicing intensive therapy, none had any prior experience with this form of treatment. All were required to state their willingness to accept either intensive or conventional therapy. As a group, they experienced substantial difficulty in following the intensive therapy regimen. Their successes can be attributed in part to the supportive use of behavioral change strategies by DCCT health professional teams. Therefore, one of the most important lessons from the DCCT is that health professionals must resist the temptation to label patients as noncompliant and accept instead that almost all can improve their glycemic

From Vanderbilt University School of Medicine (R.A.L., D.D., K.J., J.L., D.S.), Nashville, Tennessee; Washington University School of Medicine (J.B.), St. Louis, Missouri; Joslin Diabetes Center (A.J.), Boston, Massachusetts; and the Department of Psychiatry (J.K.), University of Iowa School of Medicine, Iowa City, Iowa.

Address correspondence and reprint requests to Rodney A. Lorenz, MD, 315 Medical Arts Building, 1211 21st Ave. South, Nashville, TN 37212.

Received for publication 14 August 1995 and accepted in revised form 21 December 1995.

This article is based on a presentation of the same title delivered at the Annual Scientific Meetings of The American Diabetes Association, New Orleans, June 1994.

DCCT, Diabetes Control and Complications Trial.

Table 1—Patient characteristics to assess in selecting candidates for intensive therapy

Contraindications to intensive therapy
Repeated hypoglycemia or diabetic ketoacidosis
Major mental disorder
Severe manic or depressive disorders
Schizophrenia
Substance abuse
Eating disorders
Personality disorders
Lack of financial resources
Severe family or environmental instability
Indications for moderating treatment goals
Patient expectations and priorities
Prior experience with rigorous self-care regimens
Social support

control when given appropriate assistance.

Others have made the same point (4,5). Individuals who are unable or unwilling to adopt all that intensive therapy requires can usually be assisted to make some changes that yield health benefits.

Specific behavioral interventions to facilitate intensive therapy can be considered in five categories. We call these patient selection, getting ready, initiation, maintenance, and changing health professionals. Several strategies will be listed in each category.

PATIENT SELECTION— The first practical lesson is: when considering intensive therapy, perform a comprehensive assessment, review the available treatment options, and negotiate realistic treatment goals. A primary purpose of the initial patient assessment is to identify the minority of patients who exhibit contraindications to intensive therapy (Table 1). History of repeated hypoglycemia or diabetic ketoacidosis, major mental disorder, and lack of financial resources identify patients in whom it will be difficult to achieve the therapeutic intensity needed to approach normoglycemia. A history of severe hypoglycemia predicts increased risk of severe hypoglycemia during intensive therapy (6). Repeated episodes of diabetic ketoacidosis are most often related to major psychosocial problems that impede behavioral change. Successful intensive therapy depends on access to requi-

site hardware and disposable supplies. Those personality disorders that include difficulties with impulse control and with forming lasting relationships with others are particularly problematic. Severe instability in basic life domains (e.g., divorce or homelessness) will usually prevent the focus on diabetes management that is needed to achieve optimal metabolic control safely. These contraindications are not absolute, however, because the DCCT suggested that any decrement in mean blood glucose level is associated with reduced risk of complications (1). Many patients with these characteristics can improve their glucose control to some extent and achieve some benefit. In addition, some of these characteristics may be transient or amenable to intervention.

The assessment should also screen for the other patient characteristics listed in Table 1, because they indicate a need to moderate treatment goals. Some patients have unrealistic expectations that lead to frustration and abandonment of desirable behaviors. Many have periods when one or two priorities outweigh all others. For example, a person attending college and working full time might choose to moderate treatment goals temporarily. We found it difficult to improve glucose control in patients who were not personally committed to that goal, such as adolescents whose parents demanded intensive therapy. The person who can be convinced that behavioral change holds benefits for him or her is more likely to change. Previous experience with demanding behavioral treatments such as weight loss programs may predict ability to initiate new behavioral changes. Social support generally has a positive influence on behavioral change in diabetes management (7–9) and is especially important for intensive therapy of IDDM because of the risk of hypoglycemia that requires the assistance of another person. In some instances it is difficult to achieve a high level of confidence about an individual's potential for success with intensive therapy; in such instances a short trial can be useful before a long-term commitment is made.

GETTING READY— Once the patient has committed to intensive therapy and has negotiated a treatment goal, information gained in the comprehensive

Table 2—Getting ready: strategies to use before initiating intensive therapy

Assessment
Patient's agenda, values, goals
Details of daily living
Social support
Beliefs, understanding about diabetes
Action
Build desire for change
Build social support
Present unified treatment plan
Teach problem-solving method
Prepare for ambiguity and difficulty of glucose control

assessment should be used to individualize treatment methods before initiating the program (Table 2). First, it is useful to determine the patient's values and personal agenda (10). Glycemic control is only one of many possible personal goals. Knowing all of a person's important goals can be useful in assisting with behavior change. Careful planning and negotiation can sometimes be used to make apparently contradictory goals (e.g., glycemic control and eating sweets) complementary.

Second, defining daily living routines in great detail allows the patient and provider to anticipate problems (11,12). For example, knowing where and under what circumstances the patient will be testing blood glucose may facilitate planning for that activity. Social support in the home, school, and work environments should be assessed to minimize potential conflicts and arrange for assistance when needed. Patients' and their families' beliefs about diabetes should be assessed thoroughly because they sometimes obstruct behavioral change (13,14). The belief that people with diabetes cannot eat sugar is an example; teaching a patient that eating sugar is acceptable without including other family members may lead to conflicts that impede behavioral change.

Once the provider has a firm grasp of the patient's values and goals, lifestyle, social environment, and belief structure, concrete planning for behavioral change can begin. Enthusiasm for a change in diabetes management can be enhanced by reviewing the benefits, emphasizing those that the assessment indicated were most important to the patient. Including family members in this step justifies subsequent requests for their support and participation in treatment. It is most important

during this planning process that the health care team present a single, unified treatment plan and a positive attitude about intensive therapy. Members of the team should communicate with each other throughout assessment and planning so that each team member articulates the same priorities. Confusion is almost guaranteed, for example, when the patient hears one professional emphasize diet and another emphasize insulin as the most important element of therapy.

It is also useful to instruct patients regarding problem-solving methods. The team should convey the idea that successful intensive therapy involves an ongoing process of problem-solving, adjustment, and readjustment. In other words, patients must be prepared for the trial and error process by which many details of intensive therapy regimens are determined. Preparing for the ambiguity and variability in blood glucose levels and the difficulty of achieving near-normal levels may reduce the frustration felt when the desired results are achieved slowly or not at all. In summary, before initiating intensive therapy, providers should perform a comprehensive assessment, negotiate and individualize goals and plans, and build expectations, skills, and environmental conditions that will support sustained behavioral change.

INITIATING INTENSIVE THERAPY

— Suggestions for initiating behavioral change are grouped in three categories: program for success, plan for problems, and use positive contingencies (Table 3). The program for success begins with a step that is sometimes difficult for both patients and professionals, i.e., establishing a collaborative process. For professionals, this means putting aside our egos and the tradition that says the professional knows what is best, a tradition in which most of us were socialized. It means learning to let patients decide what is best for them and promising to help them achieve their goals, even when they seem at odds with our own personal values. It means learning new behavioral intervention skills and using them to help patients achieve their goals while candidly expressing a desire to influence them toward more healthful behavior.

For patients, a collaborative rela-

Table 3—Behavioral change strategies useful in initiating intensive therapy

Program for success
Establish a collaborative process
Meet patient's agenda first
Focus on behaviors, not outcomes
Be specific: who, what, when, where, how often?
Consider gradual change
Plan frequent contact
Plan for anticipated problems
Identify solutions for
Environmental obstacles
Competing activities
Adverse effects
Teach problem solving, trial and error process
Use reminders
Use positive contingencies
Contracts
Family supports
Therapeutic relationships
Team care

tionship means being open and honest about what they are willing and not willing to do. Honesty is enhanced when health professionals communicate that problems are to be expected in the attempt to improve glycemic control.

The patient should know that he or she will not be criticized when difficulties occur, but that the team will try to understand the problem and prepare for similar future circumstances. When professionals make it clear that they want to discover the patient's priorities and place them at the top of the agenda, honesty becomes easier for all. The importance of collaboration must be emphasized in the initial discussions of intensive therapy.

The next several suggestions are the standard fare of behavioral therapy. The first is to focus on behavior rather than outcomes such as weight or blood glucose levels. Blood glucose levels are improved through attention to a detailed list of specific behaviors, such as blood glucose testing, exercise, and regulating dietary intake. The list will be somewhat different for each patient. It is essential to be as specific as possible in negotiating behavioral changes. Instead of asking patients to exercise, for example, negotiate with them exactly what they will do, when, where, how often, and for how long. Similarly, determine when in relation to daily routines they can test blood glucose, where they can do this without

unnecessary embarrassment, what supplies they will need to carry with them, etc. This level of specificity takes time but increases the likelihood that the patient will actually try new behavior and affords an opportunity to anticipate and plan for obstacles. For some patients, especially those who are not totally committed to intensification of therapy, it is helpful to plan a series of sequential changes that gradually lead to desired goals. For example, it may be best to negotiate increases in blood glucose testing, then in frequency of insulin administration, then in exercise, rather than attempting to introduce all changes at once.

Finally, many DCCT participants believe that frequent contact between patients and providers is beneficial, especially during the initiation of intensive therapy. Contact should be as frequent as resources allow, but no less than weekly at first. Even brief telephone contact allows the clinician to reinforce successful behavioral changes and to address problems quickly before frustration and discouragement supervene. Verbal reinforcement by staff for small successes can be powerfully motivating for patients.

The plan for behavioral change should account for potential problems identified by the assessment (Table 3). Many circumstances and activities of daily living will impede behavioral change, either by obstructing change directly or by competing for time and energy. The problem-solving method can be applied to these in advance. That is, potential obstacles should be identified, and the patient should be asked to brainstorm possible solutions. One is then selected for trial, and a plan is developed for evaluating the trial. Repeated use of the problem-solving approach will allow it to become a habit that can be used easily at will. It is especially important when promoting behavioral change to anticipate and plan for any adverse effects. This is crucial in intensifying diabetes therapy because of the potential impact of weight gain and increased frequency of severe hypoglycemia. A detailed discussion of measures to minimize adverse effects is beyond the scope of this report. Like environmental obstacles and competing activities, however, adverse effects should be openly discussed with the patient to identify preventive measures that can be applied during the initiation of intensive therapy.

Finally, we often underestimate

the importance of simple forgetfulness as an obstacle to behavioral change. Incorporating a new behavior in a hectic life-style can be very difficult. In our DCCT practice we made frequent use of reminders or any simple device for cuing the desired behavior. One example is to link the desired behavior, such as testing one's blood glucose, to another habitual behavior or common circumstance, such as brushing one's teeth before bed.

Using positive contingencies is a well-known principle of behavioral change. Some DCCT clinics used rewards extensively, such as incentive programs with small prizes linked to specific behaviors such as blood glucose testing or keeping food records. Contingencies should be linked to outcomes such as HbA_{1c} only when the specific behaviors needed to achieve the outcome are identified and well understood. The value of positive verbal feedback should always be remembered. In practice, contingency contracts and material rewards may be used most often with children through their parents. This introduces another principle suggested by the DCCT experience, involving the family. The family environment can support or undermine behavioral change, and often the professional can influence family members to be facilitators. Eating is the behavior most commonly cited as influenced by family, probably because eating is often done in the family setting and is closely tied to family traditions and cultural values.

The positive influence of the therapeutic relationship is underestimated by some health professionals and was probably important in the DCCT's success. Through the frequent contact mandated by the protocol, DCCT staff and patients established strong alliances directed at study goals. The point was not, however, to ask our patients to do it for us, any more than we would want them to do it for parents or any other person. Rather, we strove to help the patient feel the constant presence of an ally, something akin to a best friend, in the fight to control diabetes.

Using a team to provide care is more than a means of distributing work among several individuals, although it is indeed useful to be able to share responsibility at frustrating times. We found that different team members worked more effectively with certain patients. In addition, optimal application of intensive

Table 4—Strategies for maintenance of intensive therapy

Expect lapses, monitor and detect early
Maintain frequent contact
Change the intervention for lapses
Involve mental health professionals for major stress
Monitor team function

therapy requires a range of skills and knowledge that will rarely be found in a single individual.

In summary, to accomplish intensive therapy, we learned to use a repertoire of behavioral change strategies, often in combination and individualized for each patient. A process of thoughtful negotiation and planning, focused on integrating specific behaviors with existing demands of individuals' lives, followed by patient and persistent problem-solving, almost always produced some measure of success.

MAINTAINING BLOOD GLUCOSE IMPROVEMENTS —

Once behavioral and metabolic goals have been achieved, maintenance becomes the challenge (15). The DCCT experience suggests that the challenge of sustaining major behavior change never stops. It was the rare patient who persisted in intensive therapy independent of ongoing professional support. Several suggestions can be offered for the maintenance phase (Table 4). First, lapses in behavior should be expected. The treatment program should include ongoing monitoring of important behaviors and contact that is frequent enough to detect lapses early. Second, when lapses did occur, we found that change per se was sometimes helpful. This could mean changing the team member who was the primary contact, introducing a new incentive plan, or changing some element of the regimen, such as switching from multiple injections to pump therapy. We also learned that lapses were especially predictable with increased life stress. Marital conflict and divorce are excellent examples: blood glucose control almost always deteriorated concurrently with the marital relationship. At times of major life stress, it is useful to involve a mental health professional for additional support and guidance. Some patients will temporarily need

a more directive approach when stress reduces their coping abilities. For others, modifying goals, lowering expectations, and providing new options may be more useful. It is important to avoid criticizing patients for the decline in metabolic control as they cope with stress or crisis.

Finally, we learned that effective team function contributed to successful patient self-management. Clear role definitions and frequent communication between team members were especially important. Sometimes, irrational reactions by team members had a negative influence. An example is the tendency for staff to assume personal responsibility for patients who do not succeed, an irrational reaction because patients are responsible for their own behavior. The constant frustration of the patient who simply will not change, if taken personally, can jeopardize team morale and impair the team's ability to help other patients. We learned that the mental health professional member of the team can be very helpful in identifying and dealing with such issues.

CHANGING HEALTH PROFESSIONALS' BEHAVIOR —

The DCCT experience also taught us that often the health professional must change as much as the patient for intensive therapy to be successful (16,17). The most important change for professionals may be the one from a prescriptive to a collaborative style of interaction. Patients simply will not do all that is desirable just because we tell them, and sometimes prescribing or demanding change erects a wall between us. In addition to a collaborative style of interaction, professionals who wish to assist patients' behavioral change need to learn new skills. The strategies mentioned here may sound like common sense, but these vitally important skills are not found in most professional curricula today. Until appropriate training becomes available, a useful alternative is to recruit a mental health professional to the diabetes care team, with the idea that he or she is there for the team as much as for the patients. Finally, it should be understood that intensive therapy of IDDM is a labor-intensive undertaking. It will rarely succeed when limited to the brief, infrequent interactions typical of the acute care medical model. In summary, when behavior

change is unsuccessful, we must resist the temptation to blame the patient, but instead we should evaluate the health professionals' skills and function as a team. The intervention strategies reviewed here should also be considered when change in health professionals' behavior is needed.

The DCCT offers many practical lessons for behavioral change in diabetes care, because intensive therapy of IDDM in the DCCT was a comprehensive program of behavioral change. Few patients will achieve and maintain glycemic goals without the assistance of skilled professionals, but with carefully individualized assistance, most patients can improve measurably. Behavioral changes of similar magnitude are required of both patients and professionals. Translating the DCCT to routine care nationwide presents many substantial challenges. Among these are educating health professionals to use behavioral change strategies and organizing the health care system to support multidisciplinary team care. The DCCT has shown that investing in these strategies will pay future dividends in prevention of diabetes-related morbidity.

APPENDIX — ADDITIONAL READING

Anderson B, Rubin R: *Practical Psychology for Diabetes Clinicians*. Alexandria, VA, American Diabetes Association, 1996

Bandura A: *Social Foundations of Thought and Action: A Social Cognitive Theory*. Englewood Cliffs, NJ, Prentice-Hall, 1986

Clement S: Diabetes self-management education. *Diabetes Care* 18:117-126, 1995

Prochaska JO, Velicer WF, Rossi JS, Goldstein MG, Marcus BH, Rakowski W, Fiore C, Harlow LL, Redding CA, Rosenbloom D, Rossi SR: Stages of change and decisional balance for 12 problem behaviors. *Health Psychol* 13:39-46, 1994

Watson DL, Tharp RG: *Self-Directed Behavior: Self-Modification for Personal Adjustment*. Monterey, CA, Brooks/Cole, 1981

References

1. The DCCT Research Group: The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* 329:977-986, 1993
2. The DCCT Research Group: Implementation of conventional and intensive treatment in the Diabetes Control and Complications Trial. *Diabetes Care* 18:361-376, 1995
3. The DCCT Research Group: Adverse events and their association with treatment regimens in the Diabetes Control and Complications Trial. *Diabetes Care* 18:1415-1427, 1995
4. Johnson SB: Health behavior and health status: concepts, methods, and applications. *J Pediatr Psychol* 19:129-141, 1994
5. Glasgow RE: A practical model of diabetes management and education. *Diabetes Care* 18:117-126, 1995
6. The DCCT Research Group: Epidemiology of severe hypoglycemia in the DCCT. *Am J Med* 90:450-459, 1991
7. La Greca AM, Auslander WF, Greco P, Spetter D, Fisher EB, Santiago JV: I get by with a little help from my family and friends: adolescents' support for diabetes care. *J Pediatr Psychol* 20:449-476, 1995
8. Anderson BJ, Coyne JC: Family context

- and compliance behavior in chronically ill children. In *Developmental Aspects of Health Compliance Behavior*. Krasnegor NA, Epstein L, Johnson SB, Yaffe SJ, Eds. Hillsdale, NJ, Erlbaum, 1993, p. 77-89
9. McKelvey J, Waller DA, North AJ, Marks JF, Schreiner B, Travis LB, Murphy JN: Reliability and validity of the Diabetes Family Behavior Scale. *Diabetes Educator* 19:125-132, 1993
10. Anderson RM: Assessing patient attitudes about diabetes: implications for health care professionals. *Diabetes Spectrum* 6:150-151, 1993
11. Glasgow RE: Social-environmental factors in diabetes: barriers to diabetes self-care. In *Handbook of Psychology and Diabetes Research and Practice*. Bradley C, Ed. Berkshire, U.K., Hardwood Academic, 1994, p. 335-349
12. Irvine AA, Saunders JT, Blank MB, Carter WR: Validation of scale measuring environmental barriers to diabetes-regimen adherence. *Diabetes Care* 12:705-711, 1990
13. Carey MP, Jorgensen RS, Weinstock RS, Sprafkin RP, Lantinga LJ, Carnrike CL, Baker MT, Meisler AW: Reliability and validity of the diabetes appraisal scale. *J Behav Med* 14:43-51, 1991
14. Hurley AC: The health belief model: evaluation of a diabetes scale. *Diabetes Educator* 16:44-48, 1990
15. Marlatt GA, Gordon JR: *Relapse Prevention: Maintenance Strategies in the Treatment of Addictive Behaviors*. New York, Guilford, 1985
16. Anderson RM, Funnell MM: The role of the physician in patient education. *Pract Diabetol* 10:10-12, 1990
17. Funnell MM, Anderson RM, Arnold MS, Barr PA, Donnelly M, Johnson PD, Taylor-Moon D, White NH: Empowerment: an idea whose time has come in diabetes education. *Diabetes Educator* 17:37-41, 1991

Downloaded from http://diabetesjournals.org/care/article-pdf/19/6/648/445375/19-6-648.pdf by guest on 27 January 2022