Patient Empowerment and the Traditional Medical Model

A case of irreconcilable differences?

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The results of the Diabetes Control and Complications Trial (DCCT) have engendered an intensive review of our approach to diabetes care. With major changes in diabetes care in the offing, this is an appropriate time to review one's philosophy of diabetes care in an effort to determine whether our approach is suited to the unique requirements of this lifelong self-managed disease. Although the DCCT represents a monumental scientific achievement, it is not altogether clear how the results of this trial should be translated into improved diabetes care (1–4). As Dr. Skyler pointed out at this year's American Diabetes Association meeting (5), there are potential risks (e.g., microvascular complications that could have been delayed or prevented) in failing to recommend intensive therapy for patients for whom it would be appropriate, as well as potential risks (e.g., severe episodes of hypoglycemia and the concomitant risk of injury) of implementing intensive therapy in patients who may not be suitable candidates. Dr. Skyler's suggested solution to the aforementioned dilemma was to have patients participate in a careful informed consent process, during which they would be helped to consider both the costs and benefits of engaging in intensive therapy. This proposed solution is a clear indication that the patient must be viewed as a responsible and active decision maker in diabetes care in the 1990s and beyond.

PATIENT EMPOWERMENT— For the past 5 years, my colleagues and I have proposed that diabetes care and patient education require a new philosophical approach to patient care, i.e., an approach that recognizes the unique role and responsibilities of the patient in the daily treatment of diabetes (6). We have labeled our approach patient empowerment and have contrasted it with the more traditional medical model–compliance-oriented approach to patient care (7). The recommended changes in diabetes care resulting from the DCCT make it even more important to examine and discuss the important differences between these two approaches. In previous articles (8,9), we have argued that the fundamental difference between the two approaches to care relies on one's view of who ultimately is in charge of an individual patient's diabetes care. The traditional medical model views the physician as the final authority in the treatment of illness. Patient empowerment, on the other hand, argues that patients are in charge of their own care on a daily basis; they are, de facto, their own health care providers. In practice, diabetes care plans are sometimes the result of a process of education and discussion between the patient and members of the health care team. This care process, while functional, begs the question of ultimate responsibility for the diabetes self-management plan.

I have made numerous presentations about the philosophy of patient empowerment and how it contrasts with the traditional medical approach. It has been my frequent experience that presentations about patient empowerment often produce a visceral reaction of resistance and unease on the part of many physicians and other health professionals. Below, I propose an assessment of why this phenomenon occurs.

THE TRADITIONAL MEDICAL MODEL— Having observed and participated in the education of medical students for the past 10 years, it seems to me that the treatment of acute illness remains the dominant paradigm in their training and, subsequently, in the practice of medicine. This paradigm, referred to here as the traditional medical model, views the physician as responsible for diagnosing the illness, deciding on an appropriate treatment, and assuring that that treatment is carried out as prescribed. The classic example of the traditional medical model in action is the treatment of the hospitalized, acutely ill patient. A physician diagnoses the disease, decides if the patient should be admitted to the hospital, and then guides the subsequent care. Patients make an ini-

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DCCT, Diabetes Control and Complications Trial.

tial crucial decision in this process—to put themselves in the hands of the physician, i.e., to accept the care that the physician prescribes. The physician is then in charge of, and responsible for, treatment of the illness. The physician decides all of the following: what laboratory tests will be performed and how the results will be interpreted; what the patient will eat and whether nutrition is relevant to the treatment plan; what type and amount of medication will be given and when it will be given; whether surgery and/or invasive testing is necessary; and when the patient is well enough to leave the hospital. In this model, the physician is viewed as active, powerful, knowledgeable, and in control of the care process. The patient is viewed as passive, accepting, compliant, and dependent on the physician's medical knowledge and goodwill. Although many other health care professionals play a role in the treatment of patients in and out of hospitals, the traditional medical model is the dominant paradigm in our health care system, influencing almost all health care.

A major result of the traditional medical approach to care is that medical students, residents, and other physician trainees are taught that they will be in charge of and responsible for the treatment of illness. This approach to care is so basic to the training of physicians and the practice of medicine that it becomes intuitive to most physicians. Because it is so fundamental, the assumption that the physician is in charge of the treatment of illness can unconsciously shape the physician's attitudes and behavior. (Such assumptions can be thought of as "platform" assumptions in that they are so embedded in the psyche of the person holding them that they are not assumptions that one thinks about, but rather are assumptions from which one thinks and acts.) Society has entrusted physicians with the responsibility to be in charge of patient care, and as a consequence many physicians react negatively to suggestions that—with diabetes—it is, or should be, otherwise.

A POOR FIT — My contention in the patient empowerment model is that the traditional medical model simply does not fit the reality of daily diabetes care. Furthermore, attempts to force diabetes care into the traditional medical model have resulted in a significant amount of frustration for both patients and health care professionals. The most salient expression of this frustration is the substantial literature on patient noncompliance (10–18). Physicians and other health care professionals, in an effort to be in charge of diabetes care, have gone to great lengths to persuade patients to be compliant. When patients are "noncompliant," it is viewed as a serious problem and is a source of significant and ongoing concern for a great many health care professionals. Until recently, very little has been written about whether the concept of compliance is even valid or appropriate for diabetes care (19). Our purpose in suggesting a patient empowerment approach is based on our experience that the traditional medical model–compliance-oriented approach is inappropriate and unworkable in the treatment of diabetes. Patients carry out 95% or more of the daily self-care of diabetes. If such self-care merely involved taking a pill each morning, this issue might never have arisen, since taking a pill once a day is not nearly as difficult or intrusive on the patient's life as are many diabetes self-care regimens. However, diabetes and its self-care affect virtually every aspect of the patient's life, and patients are often asked to substantially reshape the way in which they live.

PARENT-CHILD VERSUS ADULT-ADULT RELATIONSHIPS

— Most physicians are trained to think about diabetes in terms of managing blood glucose levels. However, to manage blood glucose levels, many physicians (and other health care professionals) end up trying to direct the daily conduct of major areas (eating, physical activity, etc.) of their patients' lives in the same way that parents direct their children. Although patients want advice about how to care for their diabetes, most do not want to be directed, ordered, controlled, or blamed regarding the conduct of their daily lives. Yet patients are often treated like children when the traditional medical model is applied to daily diabetes self-care, especially in the treatment of type II diabetes. Many type II diabetic patients are unable or unwilling to carry out the difficult and often unrealistic recommendations they are given regarding weight loss and exercise. This behavior is described by health care professionals as noncompliance, which I view as a health care professional's term for disobedience.

Patient education has been viewed by many (20–23) as an attempt to extend and increase the influence of health care professionals on the behavior of their patients. Patient empowerment, on the other hand, attempts to enhance patients' ability to influence their own lives by helping them learn how to make informed choices about the care of their diabetes. In our view, diabetes education should help patients acquire the following: knowledge of the clinical management of diabetes, behavior change skills, the assertiveness and communication skills necessary to participate effectively on their health care team, and a high degree of psychosocial self-awareness so that they can make informed judgments about whether (for them) a recommended self-care plan is realistic, relevant, and sustainable. Some people would be significantly upset if they were prevented from running 5 miles every day, while others would be significantly upset if they were required to walk 1 mile. Because diabetes care is interwoven into the social, emotional, cultural, psychological, and demographic fabric of a patient's life, expertise about blood glucose control is only one element necessary for diabetes self-care. Physicians can learn to be experts in diabetes management, but only patients can be experts in the conduct of their own lives.

Patients are as conditioned to the roles and responsibilities inherent in the traditional medical model as are physicians. A major benefit of the traditional medical model is the opportunity for patients to turn over the anxiety inherent in being ill to a physician. Being cared for by a compassionate and competent physician can be an extremely rewarding experience. The patient empowerment approach to diabetes care will require a change on the part of many patients as well as health care professionals. Some patients will be unable or unwilling to assume a significant decision-making role in the treatment of their diabetes. These patients may feel that they came to the doctor (the diabetes expert) so that their diabetes care decisions would be made for them. We would not attempt to dissuade such patients from their expectations. If a patient were to say "you're the experts, you come up with my diabetes care plan," we would do so. However, I would inform those patients that as they try to apply our diabetes care plan to their lives they may discover some areas where the plan does not fit well. We would invite them to return to clinic, where we would discuss and adjust the care plan. Some of those patients would eventually develop both the capacity and the willingness to adopt a more independent, responsible, decision-making role in the management of their diabetes, while others would wish to remain more dependent. In either case, I would attempt to meet the needs of the patient. The major value underlying the empowerment philosophy is to provide care that meets the needs and expectations of people with diabetes.

The most compelling argument that I have heard to date in favor of the traditional approach to diabetes care is that the consequences of poor diabetes care not only affect patients, but have an impact on society as well. Cases of preventable blindness, kidney failure, and other preventable complications of diabetes cost our society millions of dollars each year. The loss of human resources is a further societal burden. With regard to smoking and other behaviors that have negative health consequences, it has been argued that a concerted effort to change the behavior of people to achieve societal goals is an appropriate and responsible action. I agree with these arguments when they are applied to populations (24). For example, public health campaigns that discourage smoking and encourage appropriate levels of physical activity and reasonable nutrition are all laudable activities. However, in the treatment of an individual patient, we have the ethical responsibility to put that patient's needs and interests before those of society. It is this principle that allows for the confidentiality of the physician-patient relationship even when violating such confidentiality might contribute to a societal goal. In the treatment of an individual, that person should be viewed as an end, not a means to an end. It is realistic and reasonable for health care professionals to be advocates of good diabetes care while respecting the fundamental right and responsibility of patients to make the final decisions regarding their own daily diabetes care.

We are not suggesting that physicians and other health care professionals give up being in charge of the treatment of diabetes. Rather, we are suggesting that they give up the illusion that they are in charge of the day-to-day management of diabetes. We believe that the recognition of the patient's primary responsibility in carrying out diabetes self-care requires a reorientation to the patient-physician relationship. Physicians have asked me, "You're not talking about letting patients do anything they want, are you?" I believe that this statement reflects a naive view of both our responsibility and capacity as health care professionals to let, or not let, people with diabetes do things. Nor are we advocating that physicians and other health care professionals "turn patients loose to manage their diabetes on their own." Sometimes our advocacy of patient empowerment has been interpreted to mean that we are suggesting that health care professionals stop acting like caring and controlling parents and begin acting like laissez-faire and indifferent parents. This interpretation is incorrect. We are suggesting that a parent-child relationship is inappropriate for adult diabetes care and that it be replaced by an adult-adult relationship. That relationship should be characterized by compassion, concern, and a genuine desire on the part of the health care professional to be helpful to the patient. In the post-DCCT era, with its emphasis on intensive management, it is even more important to remember that we cannot care for our patients if we do not care about them. We believe that patients should be viewed as autonomous and equal members of the health care team, whose special expertise (knowledge of self) is central to the management of their diabetes. Although for years we have described the members of health care teams as equals, it has been (at least implicitly) understood that the physician is first among equals (25). In the treatment of diabetes that status rightfully belongs to the patient.

RECOMMENDATIONS— Based on the above arguments, I would like to recommend the following:

1. We acknowledge and accept the fact that in the daily treatment of diabetes the locus of control and decision making rests with the patient.
2. Our approach to diabetes care and education focus on providing ongoing expertise and support so that patients can make informed choices about living with and caring for their diabetes.
3. We discontinue the use of pejorative terms, such as compliance, noncompliance, and adherence, and instead help patients understand the impact of their self-care choices on the control of their diabetes and quality of their lives.
4. Medical schools include training for students during their clinical years based on a new paradigm suitable for chronic disease care, health promotion, and disease prevention

(26–28) in which the physician's role is that of mentor, advisor, and coach rather than one of complete control and responsibility.

5. The initiation of patient-professional relationships for people with diabetes begin with a discussion of the unique role and responsibilities that patients have in the treatment of this disease and why those roles and responsibilities require a type of patient-provider relationship unlike that of the traditional medical model.

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