

Contrasting Patient and Practitioner Perspectives in Type 2 Diabetes Management

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Studies of self-care behaviors in the management of type 2 diabetes often focus on patient knowledge and motivation, without considering the role of practitioner orientations. Using an exploratory descriptive design, we conducted open-ended interviews with 51 type 2 diabetes patients and 35 practitioners from clinics in San Antonio and Laredo, Texas. We found critical differences between patient and practitioner goals, evaluations, and strategies in diabetes management, especially regarding such key concepts as "control" and "taking care of self." Practitioners' perspectives are rooted in a clinical context, emphasizing technical considerations, whereas patients' perspectives exist within a life-world context and foreground practical and experiential considerations. These result in very different approaches to treatment. Practitioners, presuming failed treatment indicates uncooperativeness, try to inform and motivate patients. The patients we interviewed, however, understood and were committed to type 2 diabetes self-care, but lacked full access to behavioral options due to their poverty and limited social power.

Non-Insulin Dependent Diabetes Mellitus (type 2 diabetes) is becoming alarmingly common among certain sectors of the population, particularly the ethnic and minority poor (Carter, Pugh, & Monterrosa, 1996; Flegal et al., 1991; Funnell & Merritt, 1993; Haffner, Hazuda, Mitchell, Patterson, & Stern, 1991; Martinez, 1993; Stern & Mitchell, 1996; U.S. Department of Health and Human Services, 1990). It is a dangerous disease that can have serious long-term complications such as heart disease, peripheral vascular disease, neuropathy, retinopathy, and renal disease. Left uncontrolled, type 2 diabetes can lead to blindness, heart failure, kidney failure, and lower extrem-

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ity amputation. There is strong evidence, based on the Diabetes Control and Complications Trial (DCCT) of 1,440 Insulin Dependent Diabetes Mellitus (type 1 diabetes) patients, that tight control of glucose levels can significantly reduce the risk of developing such complications in that disease (American Diabetes Association, 1997; Crofford, 1995). Although there has been no large-scale study comparable to the DCCT for patients with type 2 diabetes, and whereas there are some important differences between the two types of diabetes, (American Diabetes Association, 1997; Gorden, 1998; Tattersall & Scott, 1987), the DCCT findings have resulted in increased concern among clinicians for tight glucose control in type 2 diabetes patients.

The problem of establishing appropriate self-care behaviors in the management of type 2 diabetes has been the focus of much recent research. Such studies commonly examine patient characteristics, such as knowledge and beliefs or psychological and demographic features, and correlate these with indicators of poor control of type 2 diabetes. Intervention efforts to improve self-care, consequently, are almost exclusively designed to alter patients' understandings and attitudes. To date, little attention has been paid to the role of clinical factors and practitioner orientations in type 2 diabetes control. In this article, we will present data from a qualitative study¹ of differences between patient and practitioner perspectives in diabetes management. We examine the distinction between these two orientations as expressed in the diverse concepts of *control* held by practitioners and patients, and investigate how these differences manifest in diverse approaches to goal setting, evaluating success, and treatment strategies. We will argue that recognizing these differences may have important implications for type 2 diabetes management.

THE PROBLEM OF SELF-CARE IN TYPE 2 DIABETES MANAGEMENT

Effective management of diabetes requires complex, continual, and demanding self-care behaviors: diet control, exercise, self-monitoring of blood sugar, and taking medications several times a day. Due to the difficulty of making lifestyle changes, however, achieving effective management of type 2 diabetes has proven to be very difficult. A profusion of studies during the past several years has attempted to address this issue, but despite this extensive research attention, achieving adequate control of glucose levels in type 2 diabetes patients remains elusive (Johnson, 1992; Kurtz, 1990; Rosenstock, 1985).

A major problem in treating diabetes is that patients often fail to appropriately carry out recommended treatment behaviors. High rates of nonadherence to treatment regimens have often been noted among type 2 diabetes patients. (Cox & Gonder-Frederick, 1992; Johnson, 1992; Kurtz, 1990). Efforts to understand the basis of this nonadherence commonly focus on patient knowledge and motivation, addressing the underlying questions: Why don't patients do what they should, and how can we get them to do it? (Cox & Gonder-Frederick, 1992; Hancher Kvan & Lyons, 1991; O'Connor, Crabtree, & Abourizk, 1992; Wing, Epstein, Nowalk, & Scott, 1986).

We wish to argue that this a priori emphasis on patient characteristics may be inappropriate. There is growing evidence that differences in the concepts and perspectives of patients and practitioners exist and may be important factors affecting treatment behavior. (Hernandez, 1995; Kleinman, 1980).

Kleinman (1980) has argued that individuals vary in their explanatory models of illness and health, which are based on distinct sets of meanings, and that these meanings importantly influence how individuals act regarding treatment. He has argued that by learning to elicit patients' explanatory models, clinicians can work toward negotiating the discrepancies between their models and patients' models, thereby improving compliance, satisfaction, and subsequent use of the health facility.

Based on this framework, Cohen, Tripp-Reimer, Smith, Sorofman, and Lively (1994) have characterized patient and practitioner explanatory models of diabetes. They found practitioners' and patients' models were least congruent regarding etiology, pathophysiology, and symptom onset, and conclude that patients and practitioners focus on different domains: Patients emphasize difficulties in the social domain and the impact of diabetes on their lives, whereas practitioners see diabetes as a pathophysiological problem and are most concerned with its physical impact. They suggest that this difference between patient and practitioner perspectives may be an important factor contributing to poor management of diabetes.

Lazarus (1988), however, has criticized the explanatory models approach for failing to consider the doctor-patient relationship and the important influence of social and economic factors on clinical reality. In this article, we try to address these shortcomings by comparing the perspectives of a group of low-income Mexican and Mexican American type 2 diabetes patients in South Texas with those of practitioners treating diabetes in the same area. We go beyond describing their respective explanatory models and consider how clinical contexts versus life-world contexts differentially frame their

perspectives. We will contrast their distinct goals, criteria for evaluating success, and strategies for diabetes management.

PURPOSE OF STUDY

This study examines how the different contexts and perspectives of patients and practitioners result in distinct approaches to type 2 diabetes management. The study was designed to compare and contrast the following aspects of type 2 diabetes in the perception and practice of both patients and practitioners: goals of management, criteria for evaluating achievement of their goals, and strategies for meeting their goals.

METHOD

Participants

Fifty-one patients were interviewed in South Texas at two public clinics serving low-income patients in San Antonio and Laredo, Texas.² Patients were all self-identified Mexican and Mexican American, had had type 2 diabetes for at least 1 year, had no major impairment due to diabetes, and gave their informed consent to be interviewed in their homes. Interviewing patients at their houses increased their comfort and allowed them to talk about their views, even if these views are not acceptable to practitioners.

Thirty-six practitioners were interviewed in six public clinics and community health centers in South Texas, including San Antonio, Brownsville, Harlingen, Pharr, Laredo, and Eagle Pass. These clinics serve primarily low-income Hispanic patients. The practitioners we interviewed were all responsible for direct care of diabetes patients. In this area, type 2 diabetes is extremely common. Practitioners estimated that 50% to 60% of the patients they see daily have type 2 diabetes.

Instruments and Procedures

This study employed a qualitative exploratory descriptive design. We conducted open-ended interviews with practitioners and patients, and a review of medical chart information for each patient in the study, as well as review of the clinical literature. The interviews followed semistructured

guides consisting of questions designed to solicit unstructured responses to a consistent set of themes. The practitioner interviews focused on their concepts and experiences in treating type 2 diabetes, exploring their attitudes about treating diabetes, the difficulties they encounter, and how they address those difficulties. For example, questions included: "Thinking about a typical patient, what is your usual approach in treating diabetes?" "What are the barriers and facilitators to good patient self-care among the patients you treat?" and "How do you feel about type 2 diabetes patients? What do you like and dislike about them?"

Interviews with patients focused on illness histories, strategies for coping with diabetes, perceived barriers to care, and concepts of the illness and its treatment. For example, we asked: "How did you first find out you had diabetes?" "What kinds of things do you do to care for your diabetes? Do they help?" "How do you tell if your diabetes is under control or not?" and "In what range do you like to keep your blood sugar?"

Interviewers³ used nonleading, probing techniques to assure as complete and unbiased answers as possible (Bernard, 1990). The interviews lasted about 2 hours each. They were conducted in English or Spanish, according to the preference of the subject.⁴ All interviews were tape-recorded and transcribed.

Analysis of Data

Early in the data collection period, a series of provisional categories and a filing and retrieval system were established. All field notes and transcripts were indexed by topic. A data base was created whose variables were based on open-ended responses to relevant questions.

We developed a method for standardizing interview data, which was then content analyzed (Bernard, 1990; Miles & Huberman, 1994). This analysis took place in several steps. First, we built initial matrixes of blocks of text (quotations and summations) for each subject. For example, matrixes for patients were composed of cells displaying reported treatment behaviors, context of treatment decision-making, and perceived outcome. These initial matrixes were reviewed for trends and patterns across cases. Patterns identified in these reviews were the basis of further classification into higher-level matrixes in which themes could be identified. Finally, these were summarized into matrixes comparing patient and practitioner groups by types of goals, evaluations, treatment strategies, and their contexts.

All phases of data analysis were cross-checked in analysis conference sessions in which all personnel involved in analysis discussed specific cases

and reached consensus about how coding categories should be applied. Any anomalies or discrepancies in coding procedures were addressed and resolved during these sessions. Data classification was cross-checked in analysis conferences and by having a second researcher code 50% of the cases, comparing the results, then resolving any discrepancies.

FINDINGS

Sociodemographic Characteristics

Patients. The 51 patients interviewed ranged in age from 29 to 69 with a mean age of 52.9. They included 26 (51%) males and 25 (49%) females. All were self-identified Mexican or Mexican American. Their mean household income was about \$12,500 annually, and they had an average of 8.1 years of schooling. Nearly three fourths were unemployed at the time of the interview. Of those interviewed, 23 chose to be interviewed in Spanish and 28 in English. About half had had diabetes for 6 years or more, and about half were in good glucose control at the time of the interview, defined by glycosylated hemoglobin (HbA_{1c}) reading < 7.5 or fasting glucose reading < 180 (see Table 1).

Practitioners. Thirty-five practitioners were interviewed, including 26 physicians, 5 physician's assistants, 2 family nurse practitioners, 2 staff nurses. Their ages ranged from 25 to 68 years with a mean age of 43.3. Most (51%) were Hispanic (Mexican American 37%, and foreign Hispanic 14%). Twenty-three percent were Anglo American, and 26% were from other foreign countries, such as the Philippines, India, and the Middle East. Twenty-five were male (71%), and 10 (29%) female. The majority (62%) did not speak Spanish (see Table 2).

Perspectives in Diabetes Management

In this section, we will compare practitioners' and patients' goals, evaluations, and strategies. We define goals as the specific objectives that patients and practitioners each hold in managing type 2 diabetes (such as control of blood glucose level). Evaluation refers to the criteria each use to judge adequacy in achieving these goals. By strategies, we mean the actual procedures and tactics each implement to meet their goals.

TABLE 1: Selected Characteristics of 51 Mexican American Type 2 Diabetes Patients

	N	Percentage
Gender		
Male	26	51
Female	25	49
Occupation		
Professional	5	10
Service	2	4
Skilled labor	12	23
Unskilled labor	9	11
Housewife	5	11
(Data missing)	12	24
Employment Status		
Not working	36	71
Working	15	29
Part-time	10	19
Full-time	5	10
Type 2 diabetes duration (time since first diagnosis)		
Less than 1 year	4	8
1 to 5 years	20	39
6 years or more	27	53
Level of glucose control^a		
Good	24	47
Fair	8	16
Poor	18	35
(Data missing)	1	2
Medications		
None	4	8
Insulin	17	33
Pills	29	57
Pills and insulin	1	2
	<i>Range</i>	<i>Mean</i>
Age	29 to 69	52.9
Education (years)	1 to 14	8.1
Income (annual household)	\$5,000 to \$25,000	\$12,500

a. Classification of level of glucose control was based on a review of patients' glucose readings in their medical records during the past year. If Glycosated Hemoglobin (HbA_{1c}) readings were available, level of glucose control was classified as follows: ≤ 7.5 = good; 7.6 to 10.0 = fair; > 10.0 = poor. If only fasting glucose readings were available, classification was as follows: < 180 = good; 180 to 250 = fair; > 250 = poor.

We base our characterization of practitioner and patient perspectives primarily on themes expressed in their interviews, as well as our observations of clinical interactions and common themes found in the clinical literature.

TABLE 2: Selected Characteristics of 35 Practitioners Interviewed

	N	Percentage
Gender		
Male	25	71
Female	10	29
Profession		
Physician	26	74
Physician's assistant	5	14
Family nurse practitioner	2	6
Staff nurse	2	6
Ethnic origin		
Hispanic American	13	37
Hispanic foreign	5	14
Anglo American	8	23
Other foreign	9	26
Language		
Does not speak Spanish	22	62
Speaks Spanish	13	37
	<u>Range</u>	<u>Mean</u>
Age (years)	25 to 68	43.3

Because we have found high agreement within each group in their respective perspectives, we will treat each point of view as homogeneous in the analysis that follows. Of course, there is some range of variation among these perspectives in both groups, as there would be in any population. Because these differences were not noteworthy in terms of the argument we make here, we will not address these variations in this article.

Practitioner Perspectives

Goals. The central goal we have identified in our composite characterization of the practitioner perspective is to achieve and maintain control over type 2 diabetes. The concept of control has a dual nature in practitioners' usage. Practitioners primarily strive for control over acceptable glucose levels. In this aspect of control, their emphasis is on the pathophysiology of the disease and its long-term complications, which is thought best achieved through preventing elevated glucose levels. A second aspect of control is the related, but distinct, goal of inducing patients to control their self-care behaviors (diet, medication, exercise), through instruction and motivation. For

example, one nurse said, "Motivation is the number one characteristic the patient needs to have for good control, motivated not to eat that second plate of food, not to watch TV but instead go for a walk." A physician said: "[Getting patients to follow treatment recommendations] requires a lot of education on the part of the people who have diabetes. It also requires much more than that, like a motivation to follow what is advised or recommended."

Evaluation. In assessing the achievement of these goals, practitioners tend to collapse the dual concept of control into a single notion. Their principal criteria for evaluating achievement of control is on the basis of clinical indicators of blood glucose levels. The preferred clinical indicator is glycosylated hemoglobin (HbA_{1c}), because it is thought to give a summary picture of glucose levels over several months. If that is not available, the much more accessible, but less reliable, finger-prick measures of fasting glucose are used. Almost all of the practitioners we studied presumed in their assessment of individual patients that, if followed, the recommended treatments would be effective. Failure to achieve glucose control was therefore taken to indicate that the patient had failed to perform the recommended behaviors, and thus had not exercised behavioral control. Thus, in place of directly evaluating achievement of the goal of controlling patients' behaviors, practitioners regularly assumed that poor glucose levels indicated poor self-care behaviors. For example, a common notation in medical charts when a patient had failed to lower their glucose levels was that the patient had been noncompliant with dietary recommendations. Our clinical observations and interviews indicate that the practitioners frequently will discount patient claims to having followed their diet, based on the "evidence" that glucose levels have not improved (Hunt, Valenzuela, & Pugh, 1998).

Strategies. In formal discussions of their practices, practitioners emphasize the importance of self-care behaviors and the challenges they face in getting patients to make lifestyle changes.⁵ Assuming that people not following treatment recommendations indicates lack of knowledge and motivation, the primary strategy for promoting adherence to self-care behaviors is patient education or nutrition counseling. Frustrated practitioners often express the sentiment that if patients could only see things as they did, they would naturally behave differently. Presuming that high glucose levels mean patients are not trying, a common approach to patient education has been to present patients with fearsome scenarios about the devastating complications that might result if they fail to comply, in an effort to frighten them into treatment compliance. Some practitioners enter into threats and negotiations with patients to try to control their behaviors as well. For example, practitioners

and patients alike reported that physicians many times hold insulin out as a threat, to try to inspire patients to follow diets and adhere to oral medication schedules (Hunt, Valenzuela, & Pugh, 1997).

Patient Perspective

Goals. The central goal expressed by the patients we interviewed can be characterized as seeking ways to effectively integrate controlling their diabetes into the fabric of their lives. Their emphasis is on the impact of the disease in experiential and social terms, rather than on its physiology. For example, many patients stated that their main goal was to get control of their diabetes, despite their highly stressed lifestyles.

In contrast to the practitioners, many patients did not express their goals in terms of glucose control, but instead in terms of behavioral control. They spoke of wanting to figure out exactly what they needed to be doing and finding ways they could really do it. It was very common for frustrated patients to say things like: "I'm doing what I was told, but (my sugar) still doesn't go down," and "I don't know what I'm doing wrong, I diet, but it doesn't make any difference."

Evaluation. Although the patients we interviewed were usually very aware of and concerned about their current glucose levels, their central criteria for evaluating achievement of their goal was not so much their glucose levels, but primarily was based on assessing how well they feel and how well they are able to maintain their normal activities. In response to the question "How can you tell that your diabetes is under control?" most made reference to how they felt. An example of a typical response is: "I know my diabetes is under control when I feel good, when I have a lot of energy, I want to walk around. But when I have high blood sugar I feel dizzy, I feel like I have no strength."

We have seen that practitioners apply standardized criteria in evaluating the adequacy of self-care behavior on the basis of the expected relationship between behavior and glucose control. In contrast, patients' evaluation of the adequacy of their own behavior is not based on general principles, but instead is quite specific. Because patients are constantly in the position of having to make microdecisions about their behaviors, they evaluate the effect of those behaviors in very specific terms. They say things such as: "I ate a brownie, but my blood sugar didn't go up," "I turned down my mother's tamales, and hurt her feelings, but my glucose didn't go down,"

“Sometimes I have a reading in the normal range, but I feel so dizzy I can’t go to work. I eat something sweet, and then I can function.”

Strategies. Patients’ main challenge in living with diabetes is to balance management of their type 2 diabetes against other competing factors in their life. Discussion of their efforts for achieving this goal is commonly expressed in terms of behavioral control, which is often subsumed under a rather broad construct: *Taking Care of Myself*. The notion of Taking Care of Myself has a somewhat moral cast to it, implying self-control and doing the right things. Taking Care of Myself is a versatile concept that combines two versions of control analogous to the practitioners’ dual concept of control: control of diabetes and self-control. The comments of a 50-year-old unemployed man who has had diabetes for more than 15 years well illustrate this dual meaning. He said:

Diabetes is controllable, if we have the willpower and the desire to succeed in controlling our sugar. It’s very difficult, because although all of us who have sugar want to overcome this, some of us can and some of us can’t, because it seems like some of us don’t have the willpower . . . In the meantime, you can do something, like in my case . . . I walk, watch my diet and although it’s not perfect I do watch it a little, and take my medicine. And I think that with this, you’re doing the best for yourself. But some of us can’t do it. For this reason there are so many people that have to have amputations of the leg. . . . Nobody is exempt . . . one has to take care of themselves a lot.

Discussions of Taking Care of Myself were extremely common among those we interviewed. For example, one technique we used in the interviews was to tell a hypothetical story of a type 2 diabetes patient whose condition gradually worsened over time. We asked patients how this person might have avoided the worsening of his or her disease. Patients were remarkable in their consistency in responding to this question: “She should have taken better care of herself.”

Contrasting Interpretations of Failed Treatment

Despite their best efforts to Take Care of Myself, patients commonly find they have failed to achieve and maintain the desired level of blood glucose. (We will discuss this phenomenon in more detail below.) Patients generally respond to such experiences in one of two ways. Some patients become more and more vigilant, perhaps experimenting with making small dietary changes and closely monitoring their blood glucose, trying to pinpoint what

is hampering achieving their expected goal. Others begin to question the connection between their diet and their glucose control, and may limit or abandon their dieting efforts altogether. In both cases, patients are actively observing and processing information and seeking appropriate strategies.

Because these are low-income patients, their options in seeking appropriate strategies are profoundly limited by their scarce resource base. This was a central theme in patient discussions of their self-care behavior, which have been examined at some length elsewhere (Hunt, Pugh, & Valenzuela, 1998; Hunt et al., 1997). Monetary considerations were perhaps the most commonly cited reasons for modifying and adapting treatments. Patients reported that their economic situation influences their orientation to their illness in two important ways. First, the marginal nature of their employment makes having diabetes a serious burden. They generally have little flexibility to miss work for doctor appointments or because of symptoms of tiredness and mental confusion that often accompany very high or low glucose levels. Employers may be very unsympathetic about their health condition, and many patients fear they may lose their job if it becomes known that they have the disease. Second, nearly three fourths of those we spoke with mentioned that the cost of treatments is a serious consideration for them, in spite of sliding-scale fees for clinic visits and prescriptions. Patients found it particularly difficult to establish dietary changes on their limited budgets.

From the life-world of patients, therefore, economic considerations were a central and undeniable concern, dictating to a great extent the self-care choices they had at their command. Practitioners also discussed the role of socioeconomic factors in diabetes care, but their comments reflect their distance from the experiential aspects of managing the disease. Practitioners' comments on socioeconomic factors and self-care can be categorized into three groups. First, a few practitioners denied that patients' socioeconomic conditions present a serious barrier to the recommended treatment. One noted that even patients with high socioeconomic levels have a problem taking care of their diabetes. Another said, "I do not think [money] is an excuse . . . there is a way around the money obstacle. Because, like I said, we won't charge them, they will put it on the bill and worry about it later, so there is a way to get around that."

Second, there were practitioners who indicated that cultural practices, not socioeconomic factors, are the most important barriers to diabetes management. As one physician put it, "I think culture [is the biggest barrier to diabetes care] . . . because of food and diet customs." Others said, "Our culture down here is a culture that puts a lot of value on eating. The fatter you are the healthier," and "I think the biggest difficulty is probably their diet . . . [For

low-income patients the problem is they have not been taught how to buy healthy foods which are cheaper." Several practitioners saw culturally determined psychological orientations as the major determinant of treatment shortcomings for low-income Hispanics. For example, one physician observed, "[These patients are in] denial and don't want to change the way they live . . . and everybody is shortsighted, instead of thinking about the future they think of just the present." Another said, "If they don't feel bad they do not come in. They are not as concerned as the Anglos I have worked with."

A third group of practitioners recognized the importance of socioeconomic conditions in their patients' ability to take care of their diabetes; however, they could not find ways to integrate this into their treatment approaches. For example, one physician said,

Typically, the diabetic patient is obese, middle-aged, female, from a low socioeconomic class. This is the typical patient we see here. So I mean all of these are factors and all of these are barriers. And if you had to choose one, it would be economic, because some of them get diabetes and then they do not have the money to come to the clinic.

Although such comments were common, none proposed specific strategies for making treatment more accessible to low-income patients. Instead, they repeatedly referred to the need to better educate and motivate the patients. For example, one physician said: "I would like for them to have their own monitoring systems, affordable monitoring systems . . . [What we do is] we try to do diabetic education classes or get the patients together and give lectures teaching about diabetes."

DISCUSSION

The concept of control is central to the goals that both practitioners and patients hold in diabetes management. There are a number of meanings within the notion of control, some of which are similar between practitioners and patients, and some of which are very different. A basic meaning of control shared by both groups is implied in the often stated concept that "diabetes cannot be cured, but it can be controlled." In this sense, control refers to control of blood glucose levels. A second meaning of control important in both groups centers on the behavioral control that type 2 diabetes management requires. The emphasis here is on patients exerting self-control in following dietary and other treatment recommendations.

Despite this semantic similarity, there are many important differences in what control means in the perspectives of these practitioners and patients. The apparent similarities in use of the term *control*, however, may be superficial and disguise serious discrepancies in the way goals are defined and pursued. The difference between their perspectives is rooted in the fact that the goals of each group are embedded within complicated ongoing contexts that are quite distinct.

Clinical goals are formulated in a world where priorities and criteria for assessing them are bounded by the clinic. Metabolic processes, clinical indicators, and prescribed behaviors are the salient factors, extracted from the extraneous elements that surround them in their actual life context. In contrast, patients' goals are defined within the unbounded world of life action, where diabetes and its management compete for time, attention, and resources with all manner of trials and tribulations encountered in the jumble of ongoing life. Thus, whereas the practitioners' perspective is reductionistic, limiting itself to the elements of the clinical agenda, the patients' perspective is expansive and inclusive. It is experience-based, seeking a connection between specific behaviors and their observed outcomes within a complex life-world.

The effect of these different contexts can be seen in contrasting the practitioner and patient understandings of the meaning of failure to achieve good glucose control. We have seen that practitioners, emphasizing clinical meanings and interpretations, commonly presume that high glucose indicates an uncooperative patient who needs further motivation to exercise self-control. When limiting their perspective to the clinical context, practitioners presume the accessibility and efficacy of the recommended behaviors and concentrate on stimulating patients to control themselves. In contrast, patients, who must simultaneously respond to a multitude of factors they encounter in their life context, are regularly confronted by nonmedical factors that may compete with medically defined goals. For them, achieving behavioral control is not a simple matter of commitment to self-care, but requires constant assessment, adaptation, and compromise.

Another superficial similarity between practitioners' and patients' perspectives is evident in their criteria for evaluating achievement of their goals. Whereas patients, like practitioners, focus on controlling glucose levels, they do not assess this in the same way. Practitioners' primary means of evaluating control of diabetes is based on objective clinical indicators. They focus almost exclusively on numerical representation of glucose status as the hallmark indication of success or failure in both controlling the illness and how well controlled patient behavior is presumed to be. Patients also are

concerned with their numerical success, but their assessments are much more complex and nuanced, factoring in consideration of how they feel, how much the illness disrupts their normal life, and their observation of the impact of their actual behaviors on their illness (Hunt, Valenzuela, & Pugh, 1998).

The findings of the DCCT have inspired an increased interest among clinicians in promoting tight control of glucose levels in both type 1 and type 2 diabetes patients. Some important differences in the evolution and disease process of these two illnesses may further account for the difference we observed in the perspectives of patients and clinicians. Consistent with the findings we report here, a study of 30 type 1 diabetes patients conducted by Jayne (1993) found that type 1 diabetes patients develop strategies for self-care that are likewise predicated in a central way on the problem of integrating the illness with their everyday life. Whereas such findings have inspired increasing interest among clinicians to respond to patients' everyday constraints, their emphasis on glucose control reflects applying the DCCT model to type 2 diabetes patients without sufficient consideration of the differences in evolution and process between the two diseases. These differences may affect patient interpretations and ensuing adaptations in important ways. For example, because type 1 diabetes treatment is essentially replacement therapy, its management is relatively straightforward. Because type 2 diabetes is a much more complicated illness to manage, its course and control may vary dramatically between patients. Mercado et al. (1998) have characterized type 2 diabetes patients as having three distinct types of illness experiences: stable, oscillating, and unstable. They argue that each patient will, therefore, have drastically different experiences of the impact of the illness on their everyday lives, ranging from no perceived impact to radical disruption, which in turn importantly affects their self-care behaviors. Without careful examination of the possible physiological basis of such differences and their implications for treatment, it seems unreasonable to assume that the DCCT findings can necessarily be generalized to type 2 diabetes patients.

Because conventional type 2 diabetes treatment hinges on patient behaviors, both practitioners and patients emphasize patient behaviors in evaluating the impact of their strategies for control of the illness. The relationship between recommended behaviors and disease outcomes is, in fact, not at all direct and far from readily observed. Research shows that the effect of specific behaviors on type 2 diabetes disease status is mediated by a multitude of factors within a highly complex process. Even in relatively controlled studies, this relationship has proven to be quite intricate and difficult to

measure (Cox & Gonder-Frederick, 1992; Goodall & Halford, 1991; Johnson, 1992; Skelly, Marshall, Haughey, Davis, & Dunford, 1995). It is not altogether clear that type 2 diabetes is, in fact, controllable over the long term even when patients follow the recommended treatments. For example, some research has found that pancreatic production of insulin may decrease over time, regardless of self-care (DeFronzo & Bonadonna, 1992).

Patients and clinicians alike must struggle with the ambiguous connection between complex sets of goals and behaviors in type 2 diabetes management. In spite of this ambiguity, in dealing with individual patients, practitioners tend to presume the clinical efficacy of recommended behaviors and to judge observed outcomes as reflecting inadequate patient behavior. Their intervention strategies, therefore, focus on inducing patients to follow treatment recommendations through education and motivation. The presumption here is that patients are willfully failing to control their behavior and that practitioners need leverage to force that control.

Our conversations with patients indicate that this model of a need to incite patients to behave as they should may be inappropriate. With only one exception, all of the patients we interviewed expressed an earnest interest in properly controlling their own behavior.

Patients often discussed the practical difficulties they encountered in trying to make the dramatic changes in their lifestyle that following the recommended self-care behaviors would entail. In contrast, these considerations were rarely included by practitioners in discussions of treatment behavior, and if so, were never given a central place in their discourse. Although the practitioners often mentioned socioeconomic factors as important in self-care, they failed to integrate this consideration into explanations of patient behavior in a significant way. Instead, they consistently reverted to a clinical model focusing on patient characteristics, citing knowledge and motivation as the central explanation for failed treatment. Lacking concrete options for addressing the urgent issues of treating type 2 diabetes in low-income patients, they were left to their own devices, generating interpretations that tended to blame the victim, and to reflect broadly held stereotypes about class and ethnicity.

Our interviews indicate that, rather than needing more and more information and incentives, the central issue for many of these patients was lack of practical resources to fully perform the recommended behaviors. Because these are low-income minority patients, many lack the economic and social power that medical regimens presume patients have. They face numerous competing factors in their lives which have not been considered in the design of standard treatment recommendations. These nonmedical factors can

veritably determine the treatment behaviors to which the patients, in fact, have practical access. Many of those we interviewed subsisted on very limited financial resources, which were already strained to the limit even before they tried to make special dietary arrangements. At the same time, many had little power over their social circumstances. For example, those who were employed often were working in marginal jobs, which they feared they would lose if they took time for self-care at work. Others had no social power to influence menu choices in the household where they lived.

These socioeconomic considerations may explain at least some of the high concentration of poorly controlled type 2 diabetes among ethnic minorities, who are overrepresented among the poor and socially disempowered. Practitioners demonstrate limited ability to accommodate socioeconomic limitations in making treatment recommendations. Although most recognized the role of socioeconomic factors, their strategies focus on patients' education and motivation, presuming the central problem in poor treatment outcomes is lack of knowledge and self-control.

In contrasting patient and practitioner strategies, we see another interesting distinction between their perspectives. In practice, quite often the practitioner, in judging the adequacy of patient behavior, condenses the complex set of actions that lifestyle changes entail into a monolithic concept of controlled or uncontrolled behavior. This notion, although it may refer to multiple behaviors, is generally expressed as a simple dichotomy between the cooperative and uncooperative patient, the compliant and noncompliant. Patients, on the other hand, are in the position of having to constantly make microdecisions about these complex behaviors. Their strategies consist of an ongoing effort to balance glucose control against other competing, ongoing life events. From their perspective, they are never fully compliant or noncompliant, but judge each behavior as a single event, being a part of a long-term attempt to *Take Care of Myself*.

Our analysis suggests that, at least for our study sample, to focus intervention efforts on patient education and motivation may be inappropriate. These patients all had participated in diabetes education interventions and were already well versed in understanding type 2 diabetes and its management. For the most part, they clearly understood the dangers of the disease and what they ought to do to care for themselves. In addition to showing good comprehension of the disease and its management in interviews, they showed many signs of being highly motivated patients. For example, they had all agreed to participate in lengthy interviews about their diabetes, were willing to drive great distances, and wait for long periods to see practitioners for their diabetes care in the public clinic once every few months.

Still, due to contradictory or incomplete understandings and expectations, as well as the complexity of treatment regimens, most found it very difficult to identify specific behaviors as clearly appropriate or inappropriate, and even more difficult to apply those behaviors due to competing factors in their lives unrelated to the type 2 diabetes (Hunt et al., 1998). In caring for their diabetes on a day-to-day basis, even the most dedicated patients continually must compromise with reality, balancing treatment behaviors against the competing needs and desires they encounter in everyday life. Like previous studies, we have found that the modification and adaptation of treatment recommendations is a necessary aspect of applying the principles of self-care to the particulars of daily life. (Chrisman & Kleinman, 1983; Garro, 1988; Hunt, Browner, & Jordan, 1990; Hunt, Jordan, Irwin, & Browner, 1989; Kleinman, 1980; Rubel & O'Neil, 1978).

CONCLUSION

Patients face a sophisticated and complex task in choosing appropriate behaviors within their own life context, and this task is even more complex for those living with limited resources. There is a growing body of research that is calling for practitioners to shift from attempting to dictate behaviors in an authoritative mode to forming collaborative alliances with patients with jointly identified goals and strategies (Anderson, Funnell, Dedrick, & Davis, 1991; Funnell et al., 1991; Hamdi, 1996; Martinez, 1993).

The material we have presented here indicates that an important part of forming such a collaboration will be to recognize the distinction between practitioner and patient perspectives. In the case of chronic illnesses like type 2 diabetes, the presumption that disease outcomes reflect success or failure in having incited patients to cooperate may be inaccurate. Instead, behavioral choices may be better understood as multiple and ongoing, highly dependent on the circumstances of patients' lives, and with an impact on disease status that is diffuse and often uncertain, rather than straightforward.

Standard treatment recommendations, in fact, presume a certain access to the time and materials that patients may or may not have. It is most often left to the patients' own ingenuity to adapt those recommendations to the resources they actually have available. To be attainable and useful to patients with limited social and economic resources, clinical recommendations ought to include choices that patients are able to adapt to fit within the constraints of their resource base.

NOTES

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2. These patients include 22 recruited while waiting to see internal medicine physicians at a public clinic in San Antonio, 20 recruited through a diabetes patient education trial at the same clinic, and 9 patients of practitioners participating in a practitioner education trial at a public clinic in Laredo, who were participating in an evaluation of that program.

3. Practitioner interviews were conducted by Anne C. Larme and Ryan Buchholz. Patient interviews were conducted by Miguel Valenzuela, DeAnn Pendry, Armando Cortez, and Linda M. Hunt.

4. Translations from the original Spanish of material included in this article were performed by Linda M. Hunt.

5. Although, in actual clinical interactions for treating type 2 diabetes, physicians were observed to spend most of their time reviewing and adjusting medications, and very little time discussing the details of self-care behaviors.

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Commentaries

Commentary by Rankin

Health care provider and patient perspectives frequently conflict in the management of chronic illness. The potential for misunderstanding, however, is certainly greater in such complex and intrusive illnesses as Non-Insulin Dependent Diabetes Mellitus, or type 2 diabetes, than it is in many other chronic conditions. "Contrasting Patient and Practitioner Perspectives in Type 2 Diabetes Management" affords a unique contribution to both clinicians and researchers in their attempts to provide empathetic and appropriate care to people with type 2 diabetes.

Elucidation of the concept of *control* from patient and provider perspectives illuminates some of the complex issues related to type 2 diabetes, and I would suggest, to type 1, or Insulin-Dependent Diabetes also. Whereas providers believe that if patients follow the prescribed regimen, they will be in control, patients realize over time that control is frequently influenced by factors over which they have no control. Thus, patients and providers become frustrated at the lack of control, although neither totally understands the other's perspective. The greater the frustration of the provider, the more she or he tries to enforce compliance with the regimen, to remove patient decision-making, and to frighten the patient into control. The issue of control is equally paramount in the lives of patients with type 1 diabetes as they must also struggle to balance diet, insulin, and exercise with blood glucose levels.

The belief that providers can control or manage type 2 diabetes is infantilizing and unrealistic. Patients make decisions regarding management of their type 2 diabetes based on the context of their daily lives. Rather than trying to understand patient cooperation with the medical regimen only in terms of blood glucose, this article suggests that providers should work to understand the constraints in their patients' lives and attempt to diminish barriers rather than punish patients who are perceived as noncompliant. The study provides important insights into the tribulations that patients encounter when trying to control type 2 diabetes.

Jayne (1993, 1996) provides similar insights into type 1 diabetes, or Insulin-Dependent Diabetes Mellitus (IDDM), and the attempts of patients to normalize their lives through a process of self-regulation, defined as "the coordinating or meshing of diabetes care and everyday activities to fit each person's situation" (1996, p. 52). Although type 1 and type 2 diabetes are

very different disease conditions, as Hunt and colleagues point out, the process of self-regulating the disease and treatment regimen so that it can be better accommodated in a normal lifestyle is not unlike the efforts made by type 2 patients in this study who are more concerned with living a normal life than they are with having perfect blood glucose control. As Jayne suggests, "interventions focused on assisting clients with the analysis of their self-regulating actions and expediting problem identification and definition" may be more effective than focusing solely on blood glucose levels (1996, p. 54).

Although the subjects in Hunt and colleagues' study may be especially vulnerable to provider imperatives because of the status discrepancy, their experiences are not unlike those of Jayne's subjects who were primarily middle class and well educated. The privileged position of health care providers and the hierarchical, nonparticipatory nature of most health care systems mitigates against provider-patient dialogue that might help providers better understand the exigencies of their patients' lives. Indeed, most patients who cope with chronic illnesses report that their providers have little understanding of the intrusiveness of their illness as well as its financial and emotional costs.

The authors should be commended for this important contribution to research and clinical practice involving Non-Insulin Dependent Diabetes Mellitus. The meticulous nature of the qualitative research methods employed in this study should also be applauded. The findings demonstrate the richness of data that can be provided through qualitative methods. Last, the sensitivity of the authors to the everyday context of human lives is one that should serve as an important model for all researchers and providers.

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Commentary by Anderson

This excellent study by Hunt, Arar, and Larme makes a valuable contribution to our understanding of the perceptions of patients and health care providers regarding type 2 diabetes. The study also demonstrates the usefulness of qualitative research in addressing these issues. Much of our work (R. M. Anderson, Donnelly, & Davis, 1992; R. M. Anderson, Donnelly, & Dedrick, 1990; R. M. Anderson, Donnelly, Dedrick, & Gressard, 1991; R. M. Anderson, Donnelly, Gressard, & Dedrick, 1989; R. M. Anderson, Hess, & Hiss, 1989; Donnelly & R. M. Anderson, 1990) at the University of Michigan Diabetes Research and Training Center (MDRTC) concerning the attitudes of patients and health care professionals about diabetes has been based on the recognition of the importance of beliefs and attitudes in shaping behavior. However, the traditional approach of measuring attitudes through the use of survey questionnaires has limitations (Anderson, R. M. & Donnelly, 1990). Survey techniques allow for large-scale data collection but require sacrificing much of the phenomenological richness of the respondents' perspectives to accomplish data reduction and analysis.

When reviewing returned mail surveys from patients with diabetes, I have occasionally become frustrated because a respondent has checked both the *agree* and *disagree* boxes and then added voluminous margin notes explaining why one answer is correct in one situation and the opposite answer is correct in other situations. I was frustrated because someone had put in a great deal of time and effort completing a questionnaire that I could not use in our study. After reflecting on these instances, I realized that the experience was more frustrating for the patient filling out the questionnaire. Patients were being asked to reduce their experience to "X" in one of five boxes. Such data reduction violated the integrity and subtlety of their psychosocial experience. We have begun using more focus group studies (L. A. Anderson, Satterfield, German, & R. M. Anderson, 1996; R. M. Anderson et al., 1996) to capture some of the phenomenological complexity and richness of patients' experiences living with diabetes.

Studying the attitudes, beliefs, and perceptions of both patients and professionals is an important endeavor; for example, asking whether they believe that diabetes is a serious disease is useful if we wish to understand their diabetes care related to behavior. However, it assumes that words have shared meanings between different groups of people. Do clinicians and patients mean the same thing by the words *serious disease*? Traditional

attitude surveys do not address this problem. This study does address the tute problem. Important differences in the meanings of concepts central to diabetes and its care such as *control* and *taking care of self* are explored and described. The ramifications for patient-provider interactions in which two individuals are using the same word with differences in meaning are discussed.

Hunt and colleagues have advanced work in this area by exploring the phenomenological context that both patients and practitioners bring to diabetes care. Their study points out that practitioners' behavior can also be an expression of the subjective meanings associated with clinical concepts, role expectations, and professional socialization. The field of diabetes will be well served when there is a more balanced and iterative use of both qualitative and quantitative methodologies, each of which can compensate for the limitations of the other. Used together, these methodologies can present both a more valid and useful understanding of diabetes and its self-care. This study moves our field in that direction.

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Response by the Authors

A unique aspect of the research we have reported in this article is that it presents what is essentially a cross-cultural comparison. We have used anthropological theory and techniques to compare and contrast two diverse cultural perspectives: the clinic-world of practitioners and the life-world of patients (Mishler, 1984). Trained as medical anthropologists, we bring a relativist's eye to this research. We do not assume the greater validity of either perspective. Instead, we examine their similarities and differences, and consider how they interrelate. As the second reviewer has pointed out, qualitative methods, such as open-ended interviewing and participant observation, are increasingly recognized as useful tools for studying the vexing problems of living with chronic illness. Whereas most studies using these methods concentrate either on patients or practitioners, we have shown that focusing on both simultaneously can greatly increase understanding of the challenges each encounter.

We have seen that practitioners and patients experience mutual frustrations in managing type 2 diabetes, and that these have diverse practical and conceptual bases (Larme & Pugh, 1998). The first reviewer has pointed out that although patients and practitioners may be frustrated equally, the power to dominate decision-making and claims to legitimacy resides with practitioners due to their greater social authority and status. Whereas this was brought into high relief in our study, due to the notable status differential between these low-income minority patients and their practitioners, it seems likely that such differences will also exist with other income and ethnic groups.

The first reviewer has also noted that an essential aspect of effective care is practitioner understanding and responsiveness to the practical limitations that patients face, but this remains an elusive goal. This may, at least in part, be rooted in communication difficulties due to the gap between semantic similarities and differences, such as those we have described. As the second reviewer has suggested, although it is likely that such disjunctures exist in many areas, they are frequently disguised by the data collection methods traditionally used in health research. Further research that carefully applies qualitative methodology to examining these issues will contribute to the knowledge base needed to develop truly accessible and appropriate clinical approaches, given the context of practitioners' work and patients' lives.

When chronic illness proves difficult to control, research commonly focuses on patient attributes to explain the lack of treatment efficacy. This is

especially true in the case of ethnic minorities, whose supposed cultural beliefs and attitudes are often presumed responsible for their poor health, without consideration of their socioeconomic context or the subjective process by which individuals come to embrace them (Hunt, 1997, 1998). We have found, as the second reviewer points out, that practitioners' behavior is also a feature of subjective meanings. In contrasting practitioners' subjective meanings with those of patients, we have moved away from placing the burden of responsibility for change primarily on patients. Instead, we see that both practitioners and patients hold situated perspectives that result in distinct goals, strategies, and criteria for evaluating success. We hope that this study will be a step toward developing research and intervention approaches that privilege neither the clinic-world of practitioners nor the life-world of patients, but instead seek to understand and facilitate their effective interaction.

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