

# CONCEPTUAL MODELS IN PRACTICE

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## DIABETES MELLITUS SELF-MANAGEMENT

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Understanding your patients' thoughts about health conditions—particularly with regard to chronic disease care—can help you get them on the road to successful self-management.

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**D**iabetes mellitus (DM) is a national health problem. In 2002, an estimated 18.2 million people in the United States, or 6.3% of the population, had the disease.<sup>1</sup> In the state of South Carolina, about 300,000 residents have the diagnosis,<sup>2</sup> and it's the sixth leading cause of death in the state, claiming over 1,600 lives each year. The disease is of particular concern to the VA health care system because the prevalence of DM among veterans, at 17%, is much higher than that of the general U.S. population. In the VHA, the cost of providing health care for

patients with DM is 123% higher than that of providing care for non-diabetic patients,<sup>3</sup> and such costs rise with increased duration of the disease. What's more, this chronic disease often is accompanied by such complications as blindness, kidney failure, heart attack, stroke, and amputation. Patients with DM also experience a life expectancy reduced by five to 10 years.

Although DM requires vigilant management on the part of the patient, the traditional emphasis in care has been placed on health care providers. Unfortunately, despite the increased use of practice standards and guidelines, patient outcomes haven't improved dramatically over the past decade. Providers have long reported that their patients don't adhere to guidelines and protocols—and for numerous reasons. Previous studies have concluded that the majority of chronically ill

patients fail to recall elements of potentially important medical advice and don't always adhere to such advice, even when it is recalled. There are also many reports of nonadherence in patients without adequate health insurance. If patient outcomes are to improve, therefore, it appears that greater emphasis must be placed on the patients themselves, and particularly, on their self-management practices.

In this article, we'll detail the research study that we at the William Jennings Bryan Dorn VA Medical Center in Columbia, SC conducted in order to identify the obstacles and motivating factors faced by patients attempting to manage their DM. By applying a conceptual psychosocial model to the data gathered from patient focus groups, we were able to organize patient feedback into applicable strategies for improving treatment adherence and outcomes. These strategies

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have helped us develop a formal pilot program, which is being tested at our facility currently.

### **A CONCEPTUAL MODEL OF SELF-MANAGEMENT**

Self-management implies the daily organization and execution of tasks to control or reduce the impact of a disease on an individual's physical health. Self-management frequently is viewed as a continuum of self-care involving activities that enhance or restore health, prevent disease, or evaluate symptoms. This broad description suggests that health-related behaviors are influenced by both objective factors (such as type of illness, duration of illness, formal care, and associated disability) and subjective ones (such as the patient attitudes, beliefs, and perceptions about his or her own health). Effective self-management requires a mastery of knowledge about the condition and its treatment as well as the abilities to cope with the psychosocial problems exacerbated by a chronic disease, to perform activities aimed at managing the condition, and to apply the skills that maintain adequate psychosocial functioning. One model that incorporates such concepts of self-management is the Health Belief Model (HBM), which we used as a guide in our study of DM self-management.

The HBM, conceptualized in the 1950s and based on psychologist Kurt Lewin's social psychological theory, was developed for the express purpose of explaining individual decision making related to the avoidance of disease.<sup>4</sup> It's often been used in health services research focused on chronic disease prevention and management. In this model, perceptions of personal susceptibility to disease, serious-

ness of the condition, benefits of taking action, and barriers to action all influence the individual's attempt to avoid the development or progression of a disease or medical condition. Behaviors don't focus on improving or maintaining health, but rather on reducing the chances of contracting a disease. A person's preventive health behavior is dependent on a perception of susceptibility to a disease and the belief that its occurrence would result in cost or pain. Demographic and sociopsychological factors—as well as such variables in the health care field as length of prescribed treatment, availability of and distance to treatment, and availability of providers—can influence these personal health perceptions as well as the person's ability to self-manage a disease successfully. And several of these are beyond the actual control of the individual.

cues (for example, pain, or fear of disability, amputation, or death) and external cues (such as family pressure or the death of a friend or family member from a particular disease or health condition) that may prompt an individual to take action. Often, the intensity of such cues is related to the person's perceived susceptibility.

Because some components of the model are disease-specific, and some can't be assumed to influence individual perceptions about preventive health, it's been suggested that the model be modified to include the self-efficacy component of Albert Bandura's social learning theory (Table 1).<sup>5</sup>

Although it's been useful when applied to preventive health behaviors, the modified HBM has several limitations. Since its underlying assumption is that most people value health and respond to cues that

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The HBM identifies four specific assumptions that affect a person's decisions or actions. For an individual to take an action against disease, he or she must believe: (1) that there's personal susceptibility, (2) that the disease would have at least a moderate impact on life, and (3) that taking action would be both beneficial and possible to accomplish without having to overcome major barriers. The model describes both internal

will result in favorable health outcomes, it has a limited ability to account for variance in behaviors related to attitudes and beliefs not associated with health. The model relies on rational, intentional behavior, which may be imprudent given the spontaneity that's often characteristic of human behavior. The model does, however, offer a method of assessing decisions people make about their health and the likelihood of action.

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**OUR STUDY DESIGN**

The purpose of our qualitative study was to identify perceived barriers and facilitating factors of self-management among veterans with DM in rural South Carolina. DM requires complex, lifelong self-management and considerable effort on the part of the patient. In order to provide appropriate preparation and support for self-management behaviors, health care professionals must have a way to organize their knowledge about patients' attitudes and beliefs about the disease and its treatment. The HBM provides a useful framework for understanding and predicting adherence success or failure, and the reasons behind such outcomes. We chose the HBM as a guide for this focus group study because it's more comprehensive than other conceptual models for self-management in that it incorporates the concepts of self-efficacy and self-regulation. We used the model to organize our focus group interviews and to guide our interpretation of patient responses.

**Methods**

Our study included patients from the William Jennings Bryan Dorn VA Medical Center who were 40 years of age or older and whose medical record documented a diabetes diagnostic code and at least one glycosylated hemoglobin (HbA<sub>1c</sub>) measurement taken between September 1, 2000 and August 31, 2001. We recruited them by telephone solicitation—in random order, using a randomized number list of our current patients—and we divided them into eight focus groups. We used a script to explain the purpose of the study. As incentive for joining

**Table 1. The modified health belief model**

Concept	Definition	Application for providers
Perceived susceptibility	Person's belief about his or her chances of developing a health condition	Define risk levels; personalize risk based on a person's features or behavior
Perceived severity	Person's belief about the seriousness of a condition and its sequelae	Specify consequences of the risk and the condition
Perceived benefits	Person's belief about the efficacy of the advised action in reducing risk or seriousness of a condition	Define action to take; how, where, when; clarify the positive effects to be expected
Perceived barriers	Person's belief about the tangible and psychological costs of the advised action	Identify barriers that require reassurance, incentives, and assistance
Cues-to-action	Strategies to activate "readiness"	Identify patient's use of how-to information, promote awareness, provide reminders
Self-efficacy	Person's confidence in his or her ability to take action	Determine extent to which training and guidance in performing action contributes to desired actions

This table was adapted from the National Cancer Institute's *Theory at a Glance: A Guide for Health Promotion Practice*. Available at [cancer.gov/aboutnci/oc/theory-at-a-glance/page3](http://cancer.gov/aboutnci/oc/theory-at-a-glance/page3). Accessed June 1, 2004.

the first four groups, we offered a coupon for a free chicken sandwich at a local restaurant. Later in the study, after we received funding from a pharmaceutical company, we were able to compensate each participant in the last four groups with a \$10 payment. Participants weren't told of the compensation until they had completed the focus group session.

Each of the eight groups contained four to eight participants. Each convened at one of four study sites, chosen to provide a broad representation of the veteran population served by our medical center and to help us determine whether different barriers or facilitating factors existed in rural or urban environments. Two focus groups—one comprised of

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patients with poorly controlled DM (HbA<sub>1c</sub> at or above 9%) and one comprised of patient with better managed DM (average HbA<sub>1c</sub> at or below 7%)—were held in each of the sites. The first site was at our medical center, and participants were drawn from the surrounding urban area (with a population of approximately 500,000). Two sites were VA clinics in smaller metropolitan areas (with populations of 33,000 to 39,000). Participants at these two sites represented both rural and urban dwellers. The remaining site was in rural South Carolina, and participants either lived within the small town (population 13,700) or in the surrounding county.

While it's standard practice to make a video or audio recording of focus group sessions, due to limited resources and an absence of initial funding, we decided to only audiotape the sessions and take handwritten notes. A group facilitator used a semistructured interview guide to lead the discussions. Each topic and question was listed on a flip chart for all group participants to see. The facilitator then asked each group member to identify severity, susceptibility, threats, cues-to-action, barriers, and facilitating factors influencing their self-management of DM.

### Characteristics of participants

A total of 40 veterans participated in the focus groups (Table 2). The mean age of group members was 64.8 ± 9.2 (standard deviation) years and the majority were married, retired, and had at least a high school education. The average time since diagnosis with DM was 12.2 ± 7.9 years. Black and white patients were represented almost equally in the sample. Based on the 12-month

**Table 2. Sample characteristics of study participants**

Number of participants		40
Age (years)	Range	40–84
	Mean (SD*)	64.8 (9.19)
Race	Black	17
	White	22
	Hispanic	1
Marital status	Married	33
	Divorced/widowed/single	7
Education	High school or less	16
	Some college	24
Working status	Part-time	5
	Full-time	4
	Not working/retired	31
Years with DM <sup>†</sup>	Range	1–31
	Mean (SD)	12.2 (7.91)
Place of residence	Urban	24
	Rural	16
Latest HbA <sub>1c</sub> <sup>‡</sup> measurement	Recorded from the medical record prior to focus groups: 5.6–14.1	Three patients knew their level; 29 didn't know their level; and eight mistakenly gave their blood sugar level
People living in home	Spouse	32
	Parent(s)/sibling(s)	4
	Children (mean age)	11 (25.6)

\*SD = standard deviation. <sup>†</sup>DM = diabetes mellitus. <sup>‡</sup>HbA<sub>1c</sub> = glycosylated hemoglobin.

medical record review, HbA<sub>1c</sub> levels averaged 7.2% for the well managed DM group, 9.9% for the poorly managed DM group, and 8.5% for study participants overall. When

patients were asked to recall their latest HbA<sub>1c</sub> level, however, only three participants could do so: Most didn't even understand what was being asked.

## OUR FINDINGS

The data gathered during the focus group sessions are organized best by using the HBM. Components we addressed in this study include: perceived susceptibility, seriousness and severity, benefits, barriers; cues-to-action; and likelihood of action. Surprisingly, we found no significant differences with regard to barriers or facilitating factors based on location—urban versus rural. What's more, the responses from participants in the well managed and the poorly managed groups didn't differ appreciably from one another. Because of this, our reported responses represent the entire group unless otherwise noted.

### Perceived susceptibility

We found that, prior to diagnosis, veterans didn't view themselves as particularly susceptible to DM. When asked if they had ever imagined they would develop the disease, comments from group members included, "Never! There is no history of it in the family" and "Diabetes is something somebody else gets." Another participant said, "If you're gonna get it, you're gonna get it." These comments indicate that before being diagnosed with DM, the participants believed that there was little chance they would get the disease and if they did develop DM, there wasn't much they could have done to prevent it.

### Perceived seriousness

Many veterans stated that they saw DM as a serious disease and made comments such as, "I'm a walking nightmare," and "I'd go from here to China to get something if it cured diabetes." They told stories of people they knew who had needed amputations or

who had developed blindness or kidney problems as a result of DM, indicating that they clearly recognized the complications associated with the disease. Furthermore, they considered the disease to be a threat to their well-being. When asked about the problems DM causes for them, the group responded with the following comments: "It meant a drastic change—I had to stop working;" "I just learned to live with it;" "Getting the diagnosis was the beginning of the end;" "It's a tragedy...but life has many of those;" and "You can't plan your life...there is nothing good about it." There was a sense that even though the disease presented a serious threat to them, they felt hopeless and powerless to do anything about it. Many of the participants had a fatalistic outlook: Said one, "It's too late for me, but I don't want my grandchildren to have to face this."

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### Perceived benefits

In an attempt to determine the veterans' opinion of their own efficacy in managing DM, we asked them what they had found helpful as they attempted to reduce the impact of the disease on their lives. We also asked if there was anything good about receiving a DM diagnosis, and we received such responses as, "You can be healthier," and "You feel 100% bet-

ter when you are taking care of yourself, and this disease means you have to take care of yourself." Between the groups there was consensus that support from family or other groups improved confidence in their skills and helped them manage the disease, thus reducing its negative impact on their lives. Many veterans equated better management with better personal care and feelings of better health. Many indicated that they wanted to be around for their grandchildren and that managing their DM would help them achieve that goal.

### Perceived barriers

Our study participants cited various barriers to care. These ranged from problems with provider appointment schedules, difficult relationships with providers, lack of family support or poor attitudes on the part of family members, exercise routines that they either

didn't understand or were unable to follow because of other physical ailments, employment problems, the need for major lifestyle changes, and frustration due to lack of understanding about the disease and its management. Focus group members acknowledged that, while providers were very knowledgeable and often took time to explain medications, laboratory tests, and treatments,

such explanations often were given at a level above their comprehension. Veterans reported being told to manage their diet and exercise without being given practical information that could apply on a day-to-day basis.

Participants also indicated that adjusting to a new pattern of living was the biggest problem—especially if they didn't have strong family support. Many noted how difficult it was to have a spouse who didn't understand the disease and its required lifestyle changes. Others commented, "Working makes it [diabetes] hard to control," and "I'm tired all the time, [which] makes motivation difficult." Other barriers included a felt lack of personal responsibility; feelings of hopelessness and fatalism; the failure to understand strategies that would work for them; nonsupportive attitudes of families and employers; and, in rural communities, transportation issues.

### Cues-to-action

Veterans stated that patient education classes were helpful and offered many tips on desired activities. Many noted, however, that the classes covered too much ground at a time, and that they considered much of the content geared toward health care professionals, not patients. Participants indicated that the classes motivated them to attempt better management of their disease, but when they tried to use the information in their daily lives, their motivation waned. Interestingly, they also reported that much of the "real" information they learned about DM came from the public press rather than from their health care providers.

### Likelihood of action

Over and over, focus group participants reported that a good relationship with their providers and clear, simple instruction were important factors in managing their DM effectively. Participants asked

for group education and support sessions; "diabetes buddies" (patient partners who help one another be more accountable for DM self-management); and clear, simple written directions for diet and exercise plans that are sensitive to such cultural issues as nutritional patterns typical of certain ethnic groups. Participants indicated that developing a schedule for meals, medications, and exercise was the most important success factor. Many noted the importance of having supportive family members—who were involved in the education process—or the advice of others with DM.

We summarized the information gathered from the eight focus groups, and using the HBM to organize our the data, we came to several conclusions about the beliefs of many of our veteran patients that might influence their ability to manage DM (Table 3).

### PATIENT SUGGESTIONS AND STUDY RECOMMENDATIONS

We asked the participants what they believed might increase the likelihood of effective DM self-management and improve patient care services within the VA. They suggested offering educational classes on Saturday mornings, to better accommodate their own and their family's work schedules. They also pointed out the need for improvements in the appointment system. Frequent last minute cancellations or rescheduled appointments, they said, hamper their ability to keep appointments—particularly if they've made prior arrangements to take leave from work. The participating veterans also recommended that health care providers make lists of appropriate diets for patients (including food al-

**Table 3. Attitudes and beliefs affecting diabetes mellitus self-management among veteran patients**

Data collected in the research study conducted at the William Jennings Bryan Dorn VA Medical Center in Columbia, SC uncovered the following attitudes and beliefs about diabetes mellitus (DM) self-management among veterans in the center's service area:

- DM isn't so severe
- DM is serious, but only for someone else
- The threat of DM isn't immediate
- The benefits of managing DM aren't entirely clear
- Providers who work in "ivory towers" are a barrier to disease management
- Cues-to-action don't fit with the reality of DM self-management
- Without changes in strategies by the health care system, the likelihood of better self-management is minimal

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ternatives), recommend a physical trainer for exercise tips, schedule more frequent visits for DM care, and organize support groups for those with DM.

Based on the participants' recommendations, we were able to use the HBM to propose innovations that we expect to improve patients' ability to manage their DM. With regard to perceived severity, seriousness, and threat of DM, health care administrators should work harder to get the facts about DM out to the general public. Potential methods of doing so include having an individual with DM appear in public service announcements or news spots featuring the disease or inviting a patient who can discuss the effects of DM complications to attend a class for new patients. Concerning the patients' perceived benefit of treatment, we recommend redirecting the focus of DM care by promoting self-management as a means to an end of feeling better, of staying employed, and of enjoying quality years with grandchildren. Regarding perceived barriers to DM care, we suggest the use of actual DM patients—in addition to health care professionals—to provide patient education on the disease and its self-management. Finally, in reference to the HBM's cues-to-action component, we recommend incorporating culturally relevant recipes into diabetes meal plans and developing physical fitness regimens for people with physical limitations.

### UNDERSTANDING THE PATIENT'S PERSPECTIVE

While not surprising, this study's findings are important because they provide insight about the patient perspective of disease management. One concern we had after analyzing the focus group responses was that so few of the participants knew what their HbA<sub>1C</sub> level represented. If people don't know or understand a measurement that we use as a primary means of determining treatment efficacy, then it's no wonder they don't see a relationship between the disease and their success or failure at managing that disease. This lack of understanding is consistent with the finding that the severity of the disease isn't appreciated nor is the disease seen as an immediate threat. Cues-to-action aren't linked with the effectiveness of disease management because patients don't associate objective measures with overall disease management. In other words, while patients recognize blood sugar as a measure used in their DM care, they think of it, erroneously, as a tool used only for the immediate adjustment of medication or diet—a short-term measure, and thus, of little significance.

After reviewing our findings, we again reviewed the literature to see if other studies supported our conclusions. Wang and colleagues conducted a similar assessment using focus groups with

a patient sample of Pacific Islanders in Honolulu, HI.<sup>6</sup> The participants in that study had some of the same perceptions about complications and barriers and also suggested support groups and activities in a community-based, interactive program.

### FUTURE DIRECTIONS

DM is a disease that can't be ignored. It's costly to each of us either because of its presence within our families or society as a whole.<sup>7</sup> Our study provided us an opportunity to view the meaning of the disease for patients, and should serve to give health care professionals insight into the approaches that will be effective in promoting better DM self-management in the future. Patients are at the core of this picture; we need to listen to them and take our direction from their suggestions if we want to be successful in modifying their beliefs and health behaviors.

The information gained through these focus groups is being used to reevaluate existing approaches and to develop new, creative strategies to improve future outcomes for persons with DM. We found the HBM to be a useful framework for organizing self-management assessments, interventions, and outcomes. Some of the strategies have been developed into programs that are being tested at our facility. These include group visits; classes that emphasize the involvement of spouses and families; better follow-up after classes to clarify information and answer questions after patients have had time to "digest" the class content; the development of new teaching materials that give clear, simple, written instructions and use interesting graphics; and

experimentation with peer educators or diabetes buddies. These approaches are being implemented and outcomes are being measured using quality improvement methodology to determine the impact on the various aspects of health beliefs. Formal pilot projects have been developed and are being tested currently to determine if the interventions significantly modify health beliefs and improve self-management of DM. ●

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