ON THE COVER
Jane van Dis, University of South Dakota Medical School, Against the Grain (detail), 2000. Black and white photographs.

No One an Island: The Geography of the Whole Patient
Jodi Elgart Paik

It has become commonplace to bemoan the passing of the old-fashioned good family doctor. There is widespread concern about the lack of attention paid to the art of medicine for, despite the evolution of scientific medicine, the human heart remains the same. Thus, there is a heightened awareness of the need for physicians to address not only the biological but also the psychological, social, and cultural factors that contribute to the development and continuation of disease.

Is the growing attention paid to psychosocial issues a worthwhile endeavor, or is it, as some have argued, too much for one physician to undertake in these days of 15-minute office visits? In this issue, David Sobel gives us an answer, describing how attention to the whole patient not only yields better outcomes, but is also cost-effective.

Most medical students are well-versed in pathology, but their familiarity with life on the other side of the stethoscope often lags behind their scientific knowledge. Beyond cell counts and viral loads, what does it mean to be the person with the illness? Jane van Dis, whose stark photographs of South Dakota grace the cover of this issue, introduces us to a woman who is living with the human immunodeficiency virus in this remote locale.

More than two thirds of US citizens belong to a church or synagogue, and even more incorporate some spiritual practice into their lives. Yet the medical literature has only recently begun to include spiritual practices in its assessment of psychosocial issues. What is a physician’s role in this arena? Harold G. Koenig offers some practical suggestions for how physicians might integrate what they know about their patients’ religious beliefs into the effective practice of medicine.

Managing patients with chronic disease is the single largest source of cost for the health care system, but despite its prevalence chronic disease often receives little attention in the medical classroom. How can tomorrow’s physicians learn to share in the partnership that such patients will need? The answer, according to Martha Funnell and Robert Anderson, involves a change of perspective. Their work suggests an example of how addressing the psychosocial issues of patient care makes for better, more effective medicine.

Reflecting on his own experience as a patient, essayist Anatole Broyard observed, “Not every patient can be saved, but his illness may be eased by the way the doctor responds to him—and in responding to him, the doctor may save himself.” As they continue their training, medical students would be well advised to remember that treating a disease and caring for a patient are not necessarily the same activity.

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Mind Matters, Money Matters: The Cost-effectiveness of Mind/Body Medicine

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WHAT IF THERE WAS A NEW MEDICAL TREATMENT THAT HAD been shown in clinical trials to improve health outcomes in a number of illnesses, speed postsurgical recovery, reduce unnecessary procedures, decrease medical costs, and improve patient satisfaction? And what if its major sequela were that patients felt less isolated, more confident, satisfied, and happier, all without adverse effects? These benefits (and many others) result from a variety of nonpharmacologic mind/body and behavioral medicine treatments.

An increasing number of studies, including randomized clinical trials, point to safe and relatively inexpensive interventions that can improve health outcomes and reduce the need for more expensive medical treatments.1 Consider the following mind/body prescriptions:

Heart Disease: A study of patients with heart disease found that psychosocial interventions can reduce the risk of further cardiac events by 75% compared to those given only usual care.2 A sample of 107 patients with cardiac events by 75% compared to those given only usual care resulted in a significant decrease in rehospitalization and a reduction in the need for more expensive medical treatments.1 Consider the following mind/body prescriptions:  

Heart Disease: A study of patients with heart disease found that psychosocial interventions can reduce the risk of further cardiac events by 75% compared to those given only usual care.2 A sample of 107 patients with heart disease was randomly divided into 3 groups (usual care, exercise, and stress management) and followed up to 5 years for the incidence of myocardial infarction, bypass surgery, and angioplasty. The stress management group showed a marked difference when compared with the other 2 groups: only 10% experienced these clinical endpoints, vs 21% in the exercise group and 30% in the usual-care group.

Chronic Illness: The Chronic Disease Self-management Program, developed jointly by Stanford University and Kaiser Permanente, includes educational group sessions for patients with chronic disease. The intervention consists of a patient handbook and 7 weekly 2-hour small group sessions that focus on developing practical skills to cope with common symptoms and emotions. In a randomized clinical trial of 952 patients, those participating in the course experienced these clinical endpoints, vs 21% in the exercise group and 30% in the usual-care group.

Surgical Preparation: An important component of psychological preparation for surgery involves giving patients positive physiological suggestions and imagery. In a randomized, placebo-controlled, double-blind clinical trial, 335 patients were given 1 of 4 different audiotapes to listen to before and during surgery. A placebo group listened to a tape with a neutral white noise. Only 1 of the experimental tapes produced statistically significant benefits. This tape contained guided imagery, music, and specific suggestions of diminished blood loss and rapid healing. Patients who listened to this tape experienced a 43% reduction in blood loss and were able to leave the hospital more than a day earlier than the other groups.

Premature Infants: Certain types of pleasurable sensory stimulation are associated with positive health and cost outcomes. Pleasurable sensory stimulation can be used to improve mood, decrease recovery time, and foster healthy growth and development. Tactile stimulation appears to be vital to infant development. In 2 randomized trials premature infants who received comforting physical contact and massage 3 times a day for 10 days had 47% greater weight gain and were discharged from the hospital 5 to 6 days earlier, resulting in savings of more than $10,000 (adjusted for inflation) per infant.

If the case for mind/body medicine seems so strong from both a clinical and cost viewpoint, why has there been little investment in such integration?6 One reason is that the data are incomplete. However, even when there are good data, providers of medical and mental health services are often unaware of them. Mind/body medical interventions are often held to a higher standard of evidence than are traditional, and must justify themselves not only by improved health outcomes and quality of care, but also on the basis of cost alone. Both medical and mind/body health interventions should be judged by a similar set of criteria, and the beliefs and biases that delay the use of psychosocial interventions need to be challenged.7

While the health care system cannot be expected to address patients’ every psychosocial need, clinical interventions should better reflect the emerging evidence on the efficacy and cost-effectiveness of mind/body interventions. Mind/body medicine is not something separate or peripheral to the main tasks of medical care but should be an integral part of evidence-based, cost-effective, quality health care.

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LEAVING THE HIGHWAY, ONE DRIVES ONTO A GRASSY PLATEAU flecked with purple and yellow coneflowers. The valley below is verdant and ribbons of grasslands, soybean, and corn fields line the two-lane road. Montana claims to be Big Sky Country, but I’d take on any cowboy to tell me that the sky isn’t just as wide in this part of the world. Even more so when it brings its fearless winds switching and blustering down the Plains.

I am driving to meet Brenda (not her actual name), who is, and is not, a typical Midwesterner. She has a bold, if sometimes defiant, quality to her eyes, not unlike the stalwart spirit we associate with Midwest pioneers—Laura Ingalls Wilder’s homestead is less than 100 miles away. She slaps her hand across her knee for emphasis and her eyebrows light up easily in exclamation. Yet, there is another side to her; she has seen most of the country from the seat of her and her husband’s 18-wheeler. She’s lived in California for a stint, and 2 of her 3 children live in metropolitan areas.

South Dakota’s right-angled physique is cut up neatly into 66 counties, 64 of which are classified as “rural.” There’s a generosity of geographic expanse here that makes living with HIV/AIDS a portrait in courage. It’s safe to say the disease is and isn’t, a typical Midwesterner. She has a bold, if somewhat less health infrastructure and have unique psychosocial needs compared to their urban counterparts.

Practically speaking, one is miles from pharmacies, specialized physicians, and HIV support groups. Brenda travels 340 miles round-trip to see her infectious disease physician. A 1996 study found that 74% of rural HIV-positive persons sought HIV-related care in an urban area due to concerns about confidentiality, the perception that their doctor was not knowledgeable enough about HIV, because they were referred to another doctor, and because there wasn’t a physician in their county. Transportation barriers to that care include poor or impassable road conditions in the long winter months and a lack of public transportation.

Confidentiality concerns are also sources of anxiety among rural HIV-positive individuals and it has been demonstrated that they are less likely to seek care for HIV in their own communities. Even now, Brenda drives to a pharmacy 50 miles away rather than the nearest one (15 miles), in part because she doesn’t want to draw attention to her status. Though neighbors and shopkeepers are dispersed over larger terrain out here, there is a sometimes aggressive familiarity, an insistent knowing of one’s neighbors’ affairs. This “informal grapevine community” lays the foundation for actual and perceived discrimination that can cause profound mental and emotional stress.

Increased discrimination, lower social and family well-being, and higher perceptions of loneliness are psychosocial variables that affect HIV-positive persons in rural areas disproportionately and as such can increase psychological burdens. These sequelae concern the medical community, given that increases in psychological distress can have the effect of depressing immune function and hastening disease progression.

On a recent breezy South Dakota afternoon, I had the privilege of speaking with Brenda about some of her concerns and experiences as a rural HIV-positive individual.

How close is your nearest family? Well, my son is in Sioux Falls and that’s 170 miles away and my other 2 children are each about 500 miles away.

Do you feel like the medical support that you get is integrated; that is, is it responsive to your physical, mental and emotional health needs? Well, personally, I don’t feel like I have any choices. My infectious disease doctor takes care of my physical needs and that’s it. I was out in California [a couple of years ago] and it was totally different—there, they treat you psychologically. I felt totally different when I was out there.

Do you think your level of social support would be the same if you had, say, cancer or an illness other than HIV? I think it would be different. I think it would be easier for them [family] if it wasn’t HIV, sometimes they kind of avoid the issue. Sometimes they ask my husband, instead of me, how I’m doing. And he always says, “Fine. Fine. Everything’s fine.”... We went to town to see the fireworks [yesterday] and I actually saw a guy changing a baby diaper. And when I was growing up that was... [laughter]. The mindset in the Midwest is, I think, a little behind the times.

Could you describe what that “mindset” feels like as an HIV-positive individual? I feel that people in the [rural] Midwest have more tunnel vision in general... about a lot
of things, say, alcoholism, drugs, abuse, just in general. Prejudice seems more . . . I notice prejudice here more.

Do you think this is reflected in the Midwest as a generalized resistance to change? Yes, diversity or the lack of diversity. Most of the people who live here have lived here all their life. In California or in a metropolitan area there's more diversity of occupations and ethnicity . . . I think there's more tolerance and acceptability. To this day if I go into the cafe in Wilmont . . . everybody knows everybody and they grew up here and went to school here and what have you. I can just feel it. To me, it's more cliquey. You know, you hear about how unfriendly people are in New York or California and I don't find that at all. I find that they are more cliquey in these small rural towns. And I had a misconception, that is, I thought when I moved to the Midwest [27 years ago] that it wouldn't be like this. I had a feeling people were more friendly, more open, and they're not. I don't know if it's because people get the information later or aren't as willing to look at the truth. I think the alcohol problem and the drug problem and the child abuse and wife abuse is very much swept under the carpet here. Why? It shouldn't be.

Have you ever heard a rumor around town about your HIV status? No, I haven't heard anything about myself, but I did hear about someone else. It was at the beauty parlor—it was before I found out I had HIV—there was a young man, and the rumor in the mill around the town was that he wasn't telling girls about his HIV.

Has your sense of spirituality changed since you found out you were HIV positive? It's changed in every way. Initially I was in Alcoholics Anonymous, and part of the AA program is the spiritual. If I had found out about my HIV and had I not been in AA, I probably would not have been able to cope with it. The skills I learned in AA got me through it . . . and just for AA alone, it's hard. They have 1 meeting a week and I had to travel 50 miles [one-way] just to get to the meeting. And I was determined to make it to meetings . . . I found my comfort zone at AA, I found acceptability [with my HIV].

I'm interested in what the isolation feels like out here. What coping mechanisms you employ to keep from feeling lonely? Probably my spirituality has changed me a great deal—it's changed my notions of gratitude. You know, you live one day at a time. I think to myself, "All I have to manage is today." I garden—vegetables and flowers. And I have a mowing business, I mow lawns around here. The distance affects me here though, I can't go to a gym and exercise and I'm sometimes stuck here because of the weather. The isolation feels like out here. I know a lot of people here that have hardly been out of the county . . . I learned more about HIV in the 2 months I was out in California than when I had in the previous 2 years here in South Dakota. When I was out there, I went to an HIV clinic and they sent me to a food bank and they got me in a support group and signed me up with mental care. Whereas here, I've had to dig and scrape and holler and scream and jump up and down in order to find out anything!

I remember in our phone conversation, you said you were surprised at how much better you felt attending the support group in Sioux Falls—even though it is a long drive. Well, that's why I tried to seek that out, I really needed that contact with other people [who have HIV]. When I first contracted HIV everyone was there for me: the Red Cross, the health department. And yet, it seemed like once they knew I wasn't a threat to society, they weren't there.

What advice would you give someone who is in a rural setting dealing with this disease? To educate yourself as much as you can. To reach out to people, which is very difficult for me.

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Patients want to be seen and treated as whole persons, not as diseases. A whole person is someone whose being has physical, emotional, and spiritual dimensions. Ignoring any of these aspects of humanity leaves the patient feeling incomplete and may even interfere with healing. For many patients, spirituality is an important part of wholeness, and when addressing psychosocial aspects in medicine, that part of their personhood cannot be ignored. In this article, I use spirituality and religion interchangeably, since the vast majority of Americans do not make distinctions between these concepts. Furthermore, most research linking spirituality to health has measured religious beliefs or practices.

Many seriously ill patients use religious beliefs to cope with their illnesses. Religious involvement is a widespread practice that predicts successful coping with physical illness. In fact, high intrinsic religiousness predicts more rapid remission of depression, an association that is particularly strong in patients whose physical function is not improving. More than 850 studies have now examined the relationship between religious involvement and various aspects of mental health. Between two thirds and three quarters of these have found that people experience better mental health and adapt more successfully to stress if they are religious.

An additional 350 studies have examined religious involvement and health. The majority of these have found that religious people are physically healthier, lead healthier lifestyles, and require fewer health services. The magnitude of the possible impact on physical health—particularly survival—may approximate that of abstaining from cigarette smoking or adding 7 to 14 years to life. However, religious practices should not replace allopathic therapies. Also, while many people find that illness spurs them to ask metaphysical questions and helps them rediscover religion, no studies have shown that people who become religious only in anticipation of health benefits will experience better health.

What does all this mean for clinical practice? While no research exists on the impact of physician-directed religious assessments or interventions, some recommendations based on clinical experience and common sense can be made. First, what should physicians not do? Physicians should not “prescribe” religious beliefs or activities for health reasons. Physicians should not impose their religious beliefs on patients or initiate prayer without knowledge of the patient’s religious background and likely appreciation of such activity. Except in rare instances, physicians should not provide in-depth religious counseling to patients, something that is best done by trained clergy.

What should physicians do? Physicians should acknowledge and respect the spiritual lives of patients, and always keep interventions patient-centered. Acknowledging the spiritual lives of patients often involves taking a spiritual history. A spiritual history is not appropriate for every patient, although for those with illness that threatens life or way of life, it probably is. A consensus panel of the American College of Physicians recently suggested 4 simple questions that physicians might ask seriously ill patients: (1) “Is faith (religion, spirituality) important to you in this illness?” (2) “Has faith been important to you at other times in your life?” (3) “Do you have someone to talk to about religious matters?” and (4) “Would you like to explore religious matters with someone?” Taking a spiritual history is often a powerful intervention in itself.

The physician may consider supporting the patient’s religious beliefs that aid in coping. Religious patients, whose beliefs often form the core of their system of meaning, almost always appreciate the physician’s sensitivity to these issues. The physician can thus send an important message that he or she is concerned with the whole person, a message that enhances the patient-physician relationship and may increase the therapeutic impact of medical interventions.

Should physicians pray with patients? Post and colleagues provide guidelines for this issue. They suggest that physicians should not pray with a patient without his or her explicit request, and further state that physician-led prayer is appropriate only when a religious professional is not available, or when the patient prefers this. Alternatively, prayer can always be led by the patient. Our calling as physicians is to cure sometimes, relieve often, comfort always. If a distressed and scared patient asks for a prayer and the physician sees that such a prayer could bring comfort, then it is difficult to justify a refusal to do so. The comfort conveyed when a physician supports the core that gives the patient’s life meaning and hope is what many patients miss in their encounters with caregivers.

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The Problem With Compliance in Diabetes

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What’s the hardest thing about taking care of people with diabetes? Many health professionals would answer that patients with diabetes do not do what they are told. It is common to hear them express frustration and sorrow that their patients just don’t follow their diet or exercise plans, that they don’t check their blood sugars or even take their medicines.

Behavioral scientists have studied the problem of noncompliance (or nonadherence) extensively. They have tried to find the right approach or technique to convince patients to follow medical advice. In talking with both health professionals and people with diabetes, we have come to believe that the traditional approach to the care of diabetes and other chronic diseases may actually promote noncompliance. The adage that every system is perfectly designed for the results that it achieves is true for the way most physicians presently deliver diabetes care. While it might be appropriate for patients with acute disease to turn over responsibility for their treatment to health care experts, this method is likely to fail when health professionals try to take responsibility for the care of chronic disease. Chronic disease care is fundamentally different. It requires a different vision and a redefinition of the patient-physician relationship.1

More than 95% of diabetes care is done by the patient, and health professionals have very little control over how patients manage their illness between office visits. Patients manage their diabetes on a daily basis within the context of the other goals, priorities, health issues, family demands, and other personal concerns that make up their lives; they have the right to set goals and decide how they will manage their illness because they have to carry out those decisions and live with the consequences. Physician-directed, compliance-oriented care is not an effective approach. Because diabetes is a self-managed disease, patients are more than passive recipients of medical expertise. For diabetes care to succeed, patients must be able to make informed decisions about how they will live with their illness.

Our definition of noncompliance is 2 people working toward different goals. Diabetes care often becomes a struggle although both physicians and patients generally want positive health outcomes and good quality of life. Patients often become frustrated and dissatisfied if they feel that they are being judged and blamed for their inability or unwillingness to achieve medical goals, or if the physician does not consider their goals to be important. Once patients are viewed as collaborators who establish their own goals, the whole concept of compliance becomes irrelevant. When patients work toward their own goals, their motivation is intrinsic. Because true and lasting motivation comes from within, patients are able to make and sustain changes in their behavior using this patient-centered approach.2,3

In our work with patient empowerment we have found that this orientation leads to effective care that eliminates the problem of noncompliance. There are at least 2 steps in this process. First, roles and responsibilities need to be redefined to match the reality of diabetes care. Second, patients and physicians must create relationships that promote collaboration and partnership.4,5

We find that if physicians view themselves as experts whose job is to get patients to behave in ways that reflect that expertise, both will continue to be frustrated. However, when health professionals let go of the traditional view of provider-centered care and recognize the patient as the primary decision-maker, they become more effective practitioners.

This new vision has led to patient-provider relationships that are based on mutual expertise and responsibility. Once physicians recognize patients as experts on their own lives, they can add their medical expertise to what patients know about themselves to create a plan that will help patients to achieve their goals. We found that when health professionals actively support patients’ efforts to achieve their own goals, the resulting commitment and self-motivation leads to positive outcomes.6,7

Assessing patients’ goals, capabilities, priorities, skills, supports, and barriers puts them at the center of the interaction about disease management. One simple but powerful strategy is to start each visit by asking questions such as, “What are your concerns?” or “What would you like to get from today’s visit?” To learn about patients’ goals and priorities, ask “What’s hard for you?” “What confuses, concerns or frightens you?” “What’s most important for you?” and “How can I help you reach your goals?” The physician’s role is to assess and understand the patient, and to offer both emotional support and clinical expertise to help patients achieve their goals.

So, what can we do about the problem of noncompliance? In our experience, once health professionals eliminate the idea of noncompliance from their vision and approach to patients, it disappears as a problem.

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