Patients' Diversity Is Often Discounted

Alternatives to Mainstream Medical Treatment Call for Recognizing Ethnic, Social Differences

By Shankar Vedantam
Washington Post Staff Writer
Sunday, June 26, 2005; A01

First of three parts

When UCLA researchers reviewed the best available studies of psychiatric drugs for depression, bipolar disorder, schizophrenia and attention deficit disorder, they found that the trials had involved 9,327 patients over the years. When the team looked to see how many patients were Native Americans, the answer was . . .

Zero.

"I don't know of a single trial in the last 10 to 15 years that has been published regarding the efficacy of a pharmacological agent in treating a serious mental disorder in American Indians," said Spero Manson, a psychiatrist who heads the American Indian and Alaska Native Programs at the University of Colorado Health Sciences Center in Aurora. "It is stunning."

Native Americans are not the only group for whom psychiatrists write prescriptions with fingers crossed, the researchers at the University of California at Los Angeles found as they reviewed the data for a U.S. surgeon general's report: Of 3,980 patients in antidepressant studies, only two were Hispanic. Of 2,865 schizophrenia patients, three were Asian. Among 825 patients in bipolar disorder or manic depression studies, there were no Hispanics or Asians. Blacks were better represented, but even their numbers in any one study were too small to tell doctors anything meaningful.

In all, just 8 percent of the patients studied were minorities.

It is but one example of a larger pattern: Scientists have broadly played down the role of cultural factors in the diagnosis, treatment and outcome of mental disorders. In part, this is because modern psychiatry is based on the idea that mental illnesses are primarily organic disorders of the brain. This medicalized approach suggests that the symptoms, course and treatment of disorders ought to be the same whether patients are from the Caribbean, Canada or Cambodia.

This model has produced striking successes. Neuroscientists have uncovered key details about how the brain functions and malfunctions, and drug companies have found many effective medications. More patients than ever before have received treatments that have been proven to work.

As the population of the United States grows ever more diverse, however, this approach is facing challenges from within the profession's own ranks. A growing number of advocates for "cultural competence," many of whom are minorities themselves, warn that doctors are harming patients by ignoring evidence about the effects of ethnicity, sex, religious beliefs, social class and national origin on mental health and mental illness.

"The [drug] companies are thinking about the average Caucasian, male patient," said psychiatrist Michael Smith, at UCLA's Research Center on the Psychobiology of Ethnicity, who bemoaned the vacuum of information about drug metabolism and side effects among various groups. Some minorities' distrust of drug trials further compounds the problem, he and other researchers said.

"This thing called psychiatry -- it is a European-American invention, and it largely has no respect for nonwhite philosophies of mental health and how people function," agreed Carl Bell, a psychiatrist at the University of Illinois at Chicago.

"A lot of minority groups perceive psychiatric interventions as an ideological approach that discounts their own cultures," added Marcello Maviglia, a psychiatrist who has worked extensively with Native American patients in New Mexico. "A lot of people wouldn't be able to verbalize this, but patients know when you are discounting them, their traditions."

Leaders of mainstream psychiatry vehemently reject this critique. Darrel Regier, director of the division of research for the American Psychiatric Association, said biomedical treatments for mental disorders had been objectively shown to be superior to any other system.

"To say you want to go back to nature and have all the benefits of close-knit families take the place of psychotropic medications -- that is wishful thinking and likely dangerous," he said.

Different Viewpoints

Historically, the problem is that psychiatry has been muddled by conflicting theories about the nature of mental illnesses, Regier said. While cultural variations among groups are useful to know about, he added, it is more important for psychiatrists to home in on genetic markers and the brain mechanisms that could be universal to all patients.

"Doctors in general are reductionist," he said. "A patient walks in and you have 10 minutes to find out what in their whole life story is significant. There is a tremendous screening process to cut out irrelevant material."

Columbia University psychiatrist Robert Spitzer, who played a key role in popularizing the medical model of psychiatry, said the cultural advocates are letting politics trump science: "They don't by and large do controlled studies. They mainly complain about the biomedical model."

Spitzer and Regier reflect the eagerness among mainstream psychiatrists to move away from the mushy complexities of culture and the myriad ways in which emotional problems are expressed by different groups, and toward a straightforward system that links groups of symptoms to particular disorders. Ultimately, they hope to find neurological evidence, genetic markers and laboratory tests to differentiate mental problems.

If malfunctioning genes and neurotransmitters can be shown to cause depression, for example, these experts say doctors will be able to treat such problems at their root, making diagnosis and treatment more effective, in the same way that the discovery of the virus that causes AIDS led to highly targeted treatments.

Advocates for cultural competence counter that no matter how much science learns about the brain, culture and the environment will continue to play a huge role in why people develop emotional problems, what treatments they respond to and whether they recover. Doctors, they say, cannot afford to ignore the numerous effects of culture on diagnosis and treatment that have been documented through various streams of evidence and multiple studies in peer-reviewed publications. Among them:

· Patients with schizophrenia, a disease characterized by hallucinations and disorganized thinking, recover sooner and function better in poor countries with strong extended family ties than in the United States, two long-running studies by the World Health Organization have shown.

· People of Mexican descent born in the United States have twice the risk of disorders such as depression and anxiety, and four times the risk of drug abuse, compared with recent immigrants from Mexico. This finding is part of a growing body of literature that indicates that the newly arrived are more resilient to mental disorders, and that assimilation is associated with higher rates of psychiatric diagnoses.

· Black and Hispanic patients are more than three times as likely to be diagnosed with schizophrenia as white patients -- even though studies indicate that the rate of the disorder is the same in all groups.

· White women in the United States are three times as likely to commit suicide as black and Hispanic women -- a difference that experts attribute in part to the relative strengths of different social networks.

· A host of small studies suggests that the effects of psychiatric drugs vary widely across different ethnic groups. There are even differences in the effect with dummy pills.

Keh-Ming Lin, a psychiatrist who formerly headed the UCLA center, said that because psychiatric drugs affect behavior and change how people feel, their effects are powerfully modified by patients' beliefs.

The effects of such drugs "are not solely determined by their pharmacological properties," wrote Lin and colleagues in a book, "Psychopharmacology and Psychobiology of Ethnicity." "The prescription and use of medication is enmeshed in a process replete with social and symbolic meanings and implications."

Cultural Influence

Psychiatric diagnoses are similarly influenced by culture, said Maria Oquendo, a psychiatrist at Columbia University. Women from different cultures, for instance, face very different norms about what constitutes an ideal body weight -- and this influences the course of certain disorders: "We consider anorexia nervosa to have biological underpinnings and, therefore, universal, but in less industrialized cultures, anorexia is vanishingly rare. Culture informs our decisions on what we consider normal."

"If we understand that our definition of pathological isn't pathological in other countries, we can make better decisions on when to treat, especially with medications," she added.

Advocates for culture's role in psychiatry describe many case studies to illustrate their argument: Roberto Lewis-Fernandez was a young doctor in training in Massachusetts when he encountered a patient who was 49 and suicidal at Cambridge Hospital. The Puerto Rican woman begged for help in resolving a conflict with her son, but the Harvard University-affiliated psychiatrists focused on one set of symptoms -- she was hearing voices, seeing darting shadows and sensing invisible presences.

They diagnosed her as depressed and psychotic, or out of touch with reality, and medicated her. She was discharged. Soon after, the woman had an argument with her son and nearly killed herself by overdosing on the medication.

For Lewis-Fernandez, who is Puerto Rican, the suicide attempt confirmed his fears that his superiors had misjudged the situation. For months, as top psychiatrists ordered him to keep increasing the potency of her drugs, he had told himself that hearing voices, seeing shadows and sensing presences is considered normal in some Latino communities. But he dared not challenge the wisdom of the medical model.

"I wasn't sure if she was psychotic, but I treated her as if she was," he said about the case, which he wrote up in a medical journal. "I gave her the medicines."

When the hospital's outpatient unit evaluated the woman anew, doctors there came up with a different diagnosis. They concluded that her symptoms were not abnormal in the context of her culture -- they were expressions of distress, not illness. Lewis-Fernandez helped her reconcile with her son. She still heard voices and saw shadows, but now, as before, they did not bother her.

Unlike anti-psychiatry groups that wish to do away altogether with drugs and doctors, advocates for cultural competence argue only against one-size-fits-all thinking. Genetic vulnerabilities and brain chemistry are undoubtedly important, said Lewis-Fernandez, but

his patient was badly served because doctors assumed all her problems could be reduced to brain chemistry.

"Sure, after a certain amount of suffering for a certain amount of time, your brain reacts," he said. "The idea of mainstream psychiatry is that the pill will correct the chemical imbalance in the brain. Yes, but the imbalance keeps happening because of the situation she is in, and the pill can't correct the situation."

Minority patients are not the only ones affected: For one thing, about 40 percent of U.S. doctors training in psychiatry today are foreign-born. "There are so many international psychiatric residents that the real cross-cultural encounters are going to be between foreign physicians and white Americans," Lewis-Fernandez said. "Filipino and Indian doctors [will be] meeting your average Ohioan and saying, 'I don't understand you.' "

Nor are misunderstandings limited to issues of ethnicity. Differences between clinicians and patients in language, social class or religious belief can also be pitfalls, the advocates warn. Janice Egeland, a behavioral scientist who has worked nearly three decades with the Amish, said she realized something was very wrong when an Amish man went to a friend's house to watch baseball on TV. In the context of Amish culture, which shuns material luxuries and modern technology, his seemingly ordinary action alerted Egeland to a problem that might have been missed by a less experienced clinician. She soon discovered the man had not merely watched the game.

"He was jumping all around, pretending to run the bases," she said. After a thorough evaluation, she realized he was suffering from manic depression, a disorder characterized by alternating bouts of euphoria and depression.

In Illinois, a truck driver was diagnosed as psychotic after he said he frequently saw the devil sitting near him, warning that his life was going to take a turn for the worse. Then a doctor trained to pay attention to cultural issues realized the man was an evangelical Christian whose allegorical religious expression had been misunderstood as a hallucination by secular physicians, said Gary Myers, a clinician at Southern Illinois University in Springfield.

Mainstream psychiatrists say such examples are interesting but insist that the field stay focused on biology and brain chemistry. That is the only way to integrate psychiatry with the rest of medicine and to produce objectively verifiable treatments, said Regier, of the American Psychiatric Association.

"If you had to choose between a Western model of diagnosis and treatment and, let's say, an ayurvedic treatment model, what would you take?" he asked, referring to a traditional system of healing in India. "Whether with AIDS therapy, which the South Africans resisted, or psychotropic medicines, there is something objectively superior to a medical model of treatment of psychiatric illness."

A Common Vocabulary

Through much of the 20th century, the long shadow of Sigmund Freud hung over psychiatry. Just as doctors today talk about serotonin and brain structures such as the amygdala, doctors at mid-century evaluated patients through the lens of Freudian concepts such as transference and repression. Without common definitions of the symptoms they encountered, psychiatrists often disagreed over what ailed their patients. Show a patient to 10 psychiatrists, the joke went, and you would get 10 diagnoses.

In response, Columbia's Robert Spitzer led efforts to update American psychiatry's manual of mental disorders in 1980 and again in 1987. Experts drew up lists of specific symptoms associated with particular mental disorders -- and gave the field a common lexicon. The "Diagnostic and Statistical Manual of Mental Disorders," commonly known as DSM, became the bible of the medical model of psychiatry.

Yet, as Spitzer readily acknowledged in a recent interview, the DSM classifications did not rest on new scientific data.

"The DSM is not a scientific document," Spitzer said. "It is a bunch of smart people who studied the literature and then came up with the best way to define diseases -- very few of the categories have an empirical base." As doctors wrestled with overlapping symptoms, he said, subsequent editions greatly expanded the number of disorders: "It is not a scientific document, but it facilitates science."

Spitzer said he had never oversold the scientific credentials of the manual. But powerful factors heightened its prominence.

Drugs were shown to help patients with various symptoms, yielding hard data that most talk therapies and social interventions could not readily produce. Neuroscientists showed that many mental disorders had genetic components.

Insurance companies found that paying for pills was cheaper and simpler than paying therapists to address the interpersonal causes of suffering -- especially because general physicians could write most of the prescriptions. Patient advocates realized that defining mental illnesses as brain diseases reduced the stigma attached to depression and psychoses -- a patient could hardly be blamed for having an organic disease.

Then came Prozac. Introduced in 1988 and backed by aggressive marketing, the drug brought relief to millions and popularized the notion that depression was essentially an imbalance in brain chemistry. In short order, Prozac and other psychiatric drugs began grossing billions of dollars. Millions flowed back into television advertising, marketing to doctors and grants to organizations that supported the treatment approach.

"The pharmaceutical industry didn't create the notion of the biological revolution in American psychiatry, but it hijacked it," said Lawrence Diller, a pediatrician in Walnut Creek, Calif., and the author of "Running on Ritalin."

While defending the rise of biological psychiatry, Spitzer said his field had tried to accommodate cultural nuances. The newest versions of the diagnostic manual do include references to the role of culture, he noted. One section describes conditions that affect only small groups of people, such as “ataque *de nervios*," the very condition -- limited to Latinos, especially from the Caribbean -- that afflicted the woman whom Lewis-Fernandez treated in Cambridge.

But while the section on cultural formulations had a constituency, Spitzer said it lacks scientific support: "They insisted that these things are being ignored, so it is there, but I doubt it is used very much. I don't think the people who have developed that have done any studies to show its value. That's the difference between critics of DSM and us."

Regier, at the psychiatric association, said some advocates of cultural competence deserve credit for trying to marry cultural insights with epidemiological studies, but others are unscientific.

"You've got the cultural people who don't know how to do statistics and say you must only study individuals," Regier said. "That's like the psychoanalysts who say, 'I can't replicate it but I know it works' -- it is not a scientific discipline."

'Hardly Objective'

Advocates for culture's role in psychiatry say such criticism is disingenuous -- because it suggests the medical model itself is objective and free of bias. They point out that doctors cannot examine two brain scans and tell which belongs to a healthy person and which belongs to a patient with schizophrenia, or depression, or bipolar (manic-depressive) disorder, let alone the hundreds of other disorders in the diagnostic manual.

"Psychiatry is hardly objective," Columbia psychiatrist Oquendo said. "The instrument in psychiatry is the doctor. You talk to people in making diagnoses -- how can you say that's objective? We don't have a lab test to make a single diagnosis."

Despite its limitations, the cultural advocates say Spitzer's diagnostic model has acquired the status of gospel. Psychiatrists are too focused on fitting patients into Spitzer's categories, said psychiatrist Keh-Ming Lin, "instead of finding out from the patient where they are coming from."

"Whatever doesn't fit gets ignored, and whatever doesn't lead to medications gets ignored," Lin said.

Here and there, the advocates have made inroads. In 1999, a U.S. surgeon general's report concluded that the effects of culture on mental health "have been historically underestimated -- and they do count."

Prodded by advocates, professional organizations have added discussions of the role of culture to their meetings, and accrediting groups mandate that young doctors study how ethnicity and culture affect illness and treatment.

Insurance companies have also shown interest, said Arthur Kleinman, a psychiatrist and anthropologist at Harvard. Some HMOs, for example, have encouraged immigrants to seek out doctors who speak their native tongue. Kleinman and others welcome such moves but also worry they sometimes amount to lip service: HMO demands for efficiency, for example, have limited interactions between doctors and patients. Discussing cultural issues with a patient might add five minutes, Kleinman said, and "that's five minutes beyond an interview that usually lasts five minutes."

Driven by social, economic and technological forces, the reductionist medical approach to psychiatry is increasingly the norm around the world. Clinicians in distant countries are grappling with Spitzer's classifications in the same way that the theories of Freud once traveled from the parlors of Vienna to New York and Washington.

"What is happening with neurobiological therapy is the same thing that happened with psychoanalysis in the 1950s," said Renato Alarcon, a psychiatrist at the Mayo Clinic, referring to those who once believed Freudian therapy held all the answers.

"When science becomes a religion, it becomes scientism," he said. "There are fundamentalists among the scientists."