

MIND AND CULTURE | Psychiatry's Missing Diagnosis

Treatment Strategies Place Differing Emphasis on Family

PSYCHIATRY, From A1

"If you have a cardiovascular problem, I would prefer to be a citizen in Los Angeles than in India," said Benedetto Saraceno, director of the department of mental health and substance abuse at WHO's headquarters in Geneva. "If I had cancer, I would prefer to be treated in New York than in Iran. But if you have schizophrenia, I am not sure I would prefer to be treated in Los Angeles than in India."

Most people with schizophrenia in India live with their families or other social networks — in sharp contrast to the United States, where most patients are homeless, in group homes or on their own, in psychiatric facilities or in jail. Many Indian patients are given low-stress jobs by a culture that values social connectedness over productivity; patients in the United States are usually excluded from regular workplaces.

Indian families sit in on doctor-patient discussions because families are considered central to the problem and the solution. In America, doctor-patient conversations are confidential — and psychiatrists primarily focus on brain chemistry.

Norman Sartorius, the former head of WHO's mental health program, spearheaded the schizophrenia studies. He says there is much the United States and Europe could learn from villages such as Raipur Rani.

In an interview at his home in Geneva, he said Western countries could financially help families take care of their relatives, which would save money on hospitalization and incarceration. Caregivers might be given time off from jobs. And doctors could enlist recreational and religious groups to replace the social networks that patients lose.

"Social factors play a major and important role in the outcome of disease," Sartorius said. "Very few solutions are medical in medicine."

Decades of research have supported the WHO findings, but they have met with stony silence in the United States, in part because anti-psychiatry groups have argued erroneously that the studies prove that drugs and doctors are useless. Most U.S. psychiatrists see schizophrenia as an organic brain disorder, whose origins and outcome depend on genes and brain chemistry. They acknowledge the psychosocial aspects of disease, but the challenges of connecting patients with jobs, schooling and social networks are neglected — often because they fall outside the bounds of traditional medicine.

Asked whether he would agree that schizophrenia patients might be better off in Nigeria than in New York, Darrel Regier, director of research at the American Psychiatric Association, was blunt: "God, no!"

Regier is not alone. Patient advocacy groups are also uneasy about giving families a central role because, in a previous era, a now-discredited theory blamed schizophrenia on poor parenting.

Drug manufacturers, too, are focused elsewhere. "Pharmaceutical companies, which control the scientific production of research at universities, are not interested in saying, 'Social factors are more important than my drug,'" said Jose Bertolote, a WHO psychiatrist. "I'm not against the use of medication, but it's a question of imbalance."

Western doctors cannot write prescriptions for stronger family ties, Bertolote said. But Indian psychiatrists, unlike their Western counterparts, dispense not only drugs but also spiritual advice, family counseling — even matchmaking services. Indian doctors are seen not only as medical experts, but as wise authority figures.

In the south Indian city of Chennai, psychiatrist Shantha Kamath writes prescriptions for better family ties: When a father asked for her help in arranging the marriage of his daughter, who has schizophrenia, Kamath's written instructions told the parents how to interact with their daughter and listed the skills the young woman needed to learn before the doctor would arrange a match.

Trend Emerged Slowly

The International Pilot Study on Schizophrenia was launched in 1967 to determine whether the disease existed in all countries and whether it could be reliably diagnosed and treated.

The study quickly established that the disease occurs everywhere. Only gradually did it emerge that patients in poor nations had better



Psychiatrists Naren Wig, center, and Arun Misra meet with Krishna Devi and her grandson Nikhil in Raipur Rani, India. Devi took part in a long-term study tracking patients with schizophrenia in poor and rich countries, and her doctors say that strong social supports played an important role in her recovery.

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The complete series can be viewed at www.washingtonpost.com/nation. Washington Post staff writer Shankar Vedantam will be online at noon tomorrow at www.washingtonpost.com/liveonline to discuss his series about how culture influences the diagnosis, treatment and outcome of mental illness.

outcomes. The second study, which had more rigorous guidelines, included Naren Wig's patients in Raipur Rani village.

In all, the study tracked about 3,300 patients, Sartorius said, and 30-year follow-ups confirmed the initial trends. The study spanned a dozen countries — capitalist and communist, eastern and western, northern and southern, large and small, rich and poor.

The results were consistent — and surprising. Patients in poorer countries spent fewer days in hospitals, were more likely to be employed and were more socially connected. Between half and two-thirds became symptom-free, whereas only about a third of patients from rich countries recovered to the same degree, Sartorius said.

Nigerian, Colombian and Indian patients also seemed less likely to suffer relapses and had longer periods of health between relapses. Doctors in poorer countries stopped drugs when patients became better — whereas doctors in rich countries often required patients to take medication all their lives.

A separate study, in rural China, recently revealed that low doses of medication could be as effective as high doses, and virtually eliminated side effects, said Martin Gittelman, a clinical professor of psychiatry at New York University. And older medications, largely discarded in wealthier countries, were as effective as newer, expensive anti-psychotic drugs.

The secret? The "hand labor" of extended families and primary care workers to constantly monitor patients and bump up medication dosages at the earliest sign of psychotic flare-ups, Gittelman said. Nuclear families in more urbanized societies are often unable to provide that kind of help and monitoring, he added: "Urban Shanghai may look closer to urban New York than to rural China."

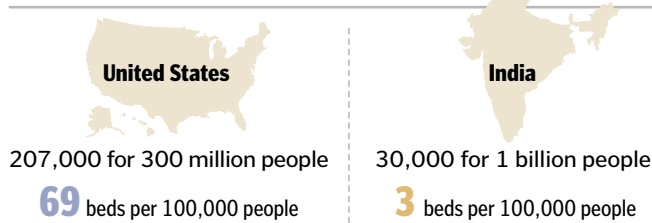
"A culture like ours is oriented around individual autonomy and accomplishment," said William Carpenter, a psychiatrist at the University of Maryland in Baltimore who helped run a wing of the WHO study in the Washington area. In countries such as Denmark, "if you were psychotic, you were on disability for life. Virtually nobody who had schizophrenia had a job."

In country after country, WHO found that strong social and family connections trumped high-tech medical facilities. Wig, the Indian psychiatrist, had just launched a psychiatry department in the north-

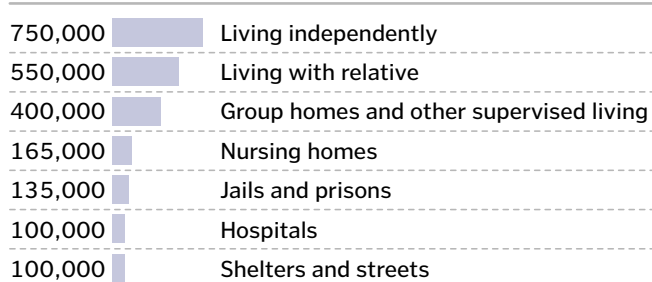
Care and Remission

Most patients with schizophrenia in India are cared for by relatives and other social networks. The United States, by contrast, relies much more on medical and public infrastructure.

NUMBER OF PSYCHIATRIC BEDS

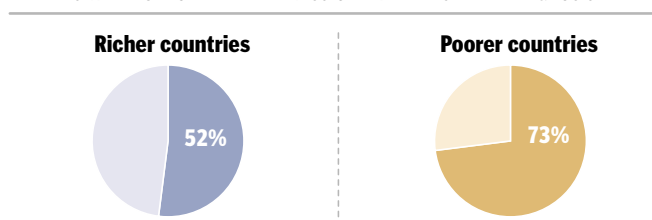


WHERE PEOPLE WITH SCHIZOPHRENIA LIVE IN THE UNITED STATES

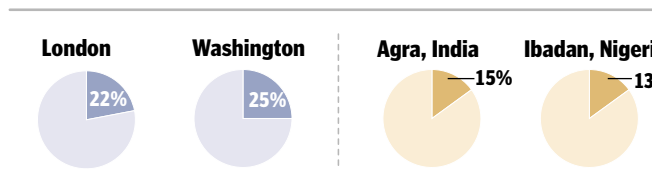


People with schizophrenia in poorer countries such as India appear to fare better than those in richer countries.

PATIENTS WITH FULL OR PARTIAL REMISSION FIVE YEARS AFTER DIAGNOSIS



PERCENTAGE OF PATIENTS WHO SPENT 75 PERCENT TO 100 PERCENT OF THE TIME IN ACUTE PSYCHOSIS FIVE YEARS AFTER DIAGNOSIS



SOURCES: Indian Journal of Medical Research, August 2004; "Surviving Schizophrenia," by E. Fuller Torrey; World Health Organization studies published in 1992 and 1996; U.S. Substance Abuse and Mental Health Services Administration

THE WASHINGTON POST



Misra visits his patient Surjit Kaur, whose grandmother Purni Kaur stays with her at the hospital. Psychiatrists at the Chandigarh hospital say relatives can soothe agitated patients better than professional nurses.

ern Indian city of Chandigarh when the second phase of the WHO study began in 1978. He had no nurses. Out of necessity, he asked families to stay with patients 24 hours a day.

Relatives became the nurses. The practice persists to this day.

The tight security found at most American psychiatric wards is absent in Chandigarh: For one thing,

it is unaffordable, but Wig also found that relatives are more effective than strangers in calming agitated patients.

Patients at the Chandigarh hospital today pay a dollar a day. That includes meals. As the WHO study got underway, Wig realized there were many patients in India who could not afford even the inexpensive hospital care. The study therefore included patients in the nearby village of Raipur Rani, where doctors could dispense outpatient care.

Krishna Devi was 22 when she was enrolled in the study. Doctors noted that her thinking was disordered — she talked about irrelevant things and turned aggressive without reason. She was paranoid and hallucinated that a man was chasing her, said Arun Misra, a psychiatrist who treated her and maintained neat, handwritten records in bound folders of now-yellowing sheets of paper.

The villagers had their own explanations for Devi's behavior — no one had heard of schizophrenia. And Devi's odd behavior was seen as no reason to keep her isolated. She got married and had five children. Devi's husband, a potter, was supportive, as were other relatives. Neighbors helped too, and in time, she said, she got better.

Wig, who trained as a psychiatrist in England, keeps up with the latest research, but mostly he tells his patients about religious figures who overcame obstacles. He never tells them schizophrenia is a chronic, incurable brain disease. And he encourages patients to complement his treatment with faith-healing techniques.

"In India, people do not accept the medical model of schizophrenia," Wig said. "The medical model says, 'This is a genetic, biochemical thing and you have to keep giving medicine and there is nothing else that can be done.' ... Indian patients continue to sustain hope."

Families Play a Crucial Role

Lakshmi Ramachandran lived in Detroit, but she decided to take her son back to India after he was diagnosed with schizophrenia in his early twenties. The family had moved to the United States when Rajesh was 2, but after he fell ill it was decided he would do better in Chennai.

"He likes the crowds — in Detroit, you had to motivate yourself to socialize," the mother said in an interview in Chennai. "Here, the neighbors come and ask, 'Hi, Rajesh, how are you?'"

Families are the reason Indian patients have better outcomes, said psychiatrist R. Thara Srinivasan, who heads a nonprofit treatment facility called the Schizophrenia Research Foundation (SCARF) in Chennai. The foundation has independently verified the WHO study results.

"My theory is that the family here ensures they take medication properly," said the psychiatrist, who prefers to be identified by the single name Thara. "Compliance is a problem in the West."

If patients refuse medication, Thara instructs families to crush the pills and disguise the medicine

in food. During a reporter's visit, another SCARF psychiatrist, Shantha Kamath, paid a small amount of money to her patient for taking an anti-psychotic injection — a reward he has now come to expect.

Westerners have criticized such practices, but Thara argues that patient-doctor relationships in India are fundamentally different from those in America: The relationships may be paternalistic, but the benefits are lower costs and less fragmentation. On an annual budget of \$67,000, SCARF treats 1,200 patients, dispenses free drugs, runs three residential facilities for 150 patients and offers vocational training each day for 100 patients.

Social connectedness for patients is seen as so important that the psychiatrists tell families to secretly give money to employers so that patients can be given fake jobs, work regular hours and have the satisfaction of getting "paid" — practices that would be unethical, even illegal, in the United States.

While work and family are clearly beneficial for patients, Thara acknowledged that caregivers, who are usually women, pay a price.

"My parents told me to get married," said one Chennai woman, C. Chitra, whose marriage was arranged when she was 23. Her in-laws, who came from a wealthier family, had told her only that her husband-to-be sometimes "got angry."

Chitra thought nothing of it: "Everyone gets angry."

But her 34-year-old husband had schizophrenia. "He hit me without reason," she said.

Chitra did not consider divorce: She felt her options as a poor, divorced woman would be worse. Shortly thereafter, her husband's brother moved in with them — and he had schizophrenia, too. Chitra cared for both men, dealt with their psychoses and calmed them when they turned violent.

Her husband slowly got better. Chitra had a baby, and she said she finally is happy. But when her in-laws wanted to arrange a marriage for her husband's brother, she put her foot down. She did not want another woman to go through what she had endured.

Battling Social Withdrawal

Prince George's County outside Washington was one of the sites of the pioneering WHO study — William Carpenter helped treat about 90 schizophrenia patients at three hospitals. That experience brought home to him the fact that medications primarily control patients' delusions and hallucinations, not the "negative" symptoms that cause patients to disappear into silent, inner worlds.

"The bias has always been in the direction of reducing psychosis," said Carpenter, director of the Maryland Psychiatric Research Center. "Psychosis is public and bothersome. ... Negative symptoms bother you if it's your child, but it doesn't create a public disturbance."

Anti-psychotic drugs that help quell the outward symptoms may actually exacerbate social withdrawal, he said: "While we treat one part of the illness, we potentially complicate another part of the illness."

New medicines are being aimed at the negative symptoms. But Carpenter and other experts said it is clear that drugs cannot replace social supports.

Treating schizophrenia without anti-psychotic drugs is unthinkable, Wig and Saraceno said. But the current system in wealthy countries merely brings patients who are in crisis into hospitals, stabilizes them with drugs and discharges them after a few days. Saraceno said that approach is doomed to end in a new crisis — the familiar "revolving door."

Ronald Manderscheid, a public health expert at the U.S. Substance Abuse and Mental Health Services Administration, said policymakers have come to understand that the key to treating schizophrenia lies in integrating cultural and social supports with medicine, as villages such as Raipur Rani have long done.

"Is it possible that a mental health system which is poor, deprived, with no resources, no drugs is providing better and more humane and sensible service to the population rather than in rich countries?" WHO's Saraceno asked. "Good mental health service doesn't require big technologies but human technologies. Sometimes, you get better human technologies in the streets of Rio than in the center of Rome."

About This Series

YESTERDAY

Modern psychiatry asserts that mental illnesses are basically organic disorders of the brain. But a growing number of psychiatrists, many of whom are minorities, say doctors are ignoring the role of ethnicity, sex, nationality and religious beliefs in the origin and outcome of mental disorders.

TODAY

A little-known study by the World Health Organization discovered that the outcome of schizophrenia, a deadly mental illness involving hallucinations and disordered thinking, is better in poor countries with limited medical infrastructure than in rich countries such as the United States. Scientists have struggled for decades to explain why.

TOMORROW

Blacks and Hispanics in the United States are far more likely to be diagnosed with serious psychotic disorders than whites. Now, a group of experts who advocate "cultural competence" are asking whether bias may influence psychiatric diagnosis.