

Letters from readers are welcomed. They will be published at the editor's discretion as space permits and will be subject to editing. They should not exceed 500 words with no more than three authors and five references and should include the writer's telephone and fax numbers and e-mail address. Letters related to material published in *Psychiatric Services* will be sent to the authors for possible reply. Send letters to John A. Talbott, M.D., Editor, *Psychiatric Services*, American Psychiatric Association, 1400 K Street, N.W., Washington, D.C. 20005; fax, 202-682-6189; e-mail, psjournal@psych.org.

Consumer Preferences for Psychiatric Research

To the Editor: Traditional research, by placing researchers apart from and above research subjects, does not readily promote genuine collaboration between researchers and study participants (1). Recently, the National Institute of Mental Health (NIMH) asserted that "establishing a research agenda that is responsive to the needs and priorities of key stakeholders is likely to increase the usefulness of research results" (2). Moreover, it is critical that such consumer input reflect the views of indigent and minority persons who constitute disproportionately large subgroups of the nation's seriously mentally ill population, especially those with schizophrenia (3).

Surprisingly, a PsycINFO search revealed no studies of the research priorities of users of psychiatric clinics during the past decade. To gain a better understanding of the priorities of this group, we conducted an exploratory study with patients of a psychiatric clinic in Brooklyn in November and December 1998. All cognitively intact patients were asked to complete an anonymous questionnaire in which they identified the five most important and five least important items from a list of 15 randomly

distributed topics for psychiatric research. Respondents could add items, but rarely did so.

Over two months, 140 persons, representing 40 percent of eligible patients, completed the survey. The mean \pm SD age of the respondents was 46 \pm 14 years. Sixty-four percent were African Americans, of whom 28 percent were Afro-Caribbean; 19 percent were Caucasian, 14 percent were Latino, and 3 percent were from other ethnic groups. Fifty-eight percent had been in treatment five or more years. Their demographics resembled those of the entire clinic; the details have been reported previously (4).

Because the questionnaire was completed anonymously, we could not determine the respondents' diagnoses. However, excluding dementia patients, the diagnostic distribution of patients at the clinic was schizophrenia, 31 percent; affective disorder, 36 percent; anxiety disorder, 22 percent; and other diagnoses, 12 percent.

Six items were ranked as most important by 40 percent or more of the respondents. These items called for more research on brain chemicals that cause mental illness (61 percent), how society affects mental illness (46 percent), drugs to treat mental illness (44 percent), family therapy as a treatment for mental illness (41 percent), the effects of poverty on mental illness (41 percent), and the use of vocational training and rehabilitation for mentally ill persons (40 percent). A principal components factor analysis with varimax rotation indicated that the 15 items that were being rated for importance could be divided into four broad categories: the effects of society, poverty, and racial discrimination; the effects of brain chemicals, genetics, and drugs; the effects of family therapy and the family; and the effects of other variables.

The least important items were more evenly distributed, with only one item, the effects of sexism or gender discrimination on mental illness, considered least important by

40 percent or more of the respondents. Other items ranked as least important were effects of racial or ethnic discrimination on mental illness (39 percent), effects of neighborhood on mental illness (26 percent), effects of poverty and income on mental illness (25 percent), and psychotherapy for mental illness (24 percent).

This survey of one segment of the consumer population should be at least partly reassuring to the designers of the national psychiatric research agenda because the most commonly endorsed cluster of important items concerned research on brain chemicals and drugs to treat mental illness. Both of these items have been priorities of NIMH and the National Alliance for the Mentally Ill (NAMI) (2,5). However, a second cluster of responses that focused on the social etiology of mental illness, such as the effects of poverty and society, has had substantially lower priority for NIMH and NAMI. Presumably, these consumers' everyday experiences have made them keenly interested in the role social forces play in influencing psychiatric well-being. This finding suggests that greater priority should be given to understanding patients' social context and their experiential knowledge.

Carl I. Cohen, M.D.

Dr. Cohen is professor and director of geriatric psychiatry at the State University of New York Health Science Center at Brooklyn.

References

1. Bond MA: Defining the research relationship: maximizing participation in an unequal world, in *Researching Community Psychology: Issues of Theory and Methods*. Edited by Tolan P, Keys C, Chertok F, et al. Washington, DC, American Psychological Association, 1990
2. Bridging Science and Service. Rockville, Md, National Institute of Mental Health, Clinical Treatment and Services Research Workgroup, National Advisory Mental Health Council, 1998
3. Keith SJ, Regier DA, Rae DS: The schizophrenic disorders, in *Psychiatric Disorders in America*. Edited by Robins LN, Regier DA. New York, Free Press, 1991

4. Cohen CI: The impact of welfare reform as perceived by users of mental health services in New York City. *Psychiatric Services* 48:1589–1591, 1997
5. National Institute of Mental Health Research Funding. Arlington, Va, National Alliance for the Mentally Ill, 1999. Available at www.nami.org/update/unitednimh.html

Medicaid and CMHCs

To the Editor: Community mental health centers (CMHCs) depend on revenue from Medicaid to create systems of community support for persons with acute and chronic mental illnesses. Medicaid gives this vulnerable population access to a full continuum of mental health care that may exceed the level of care available to insured, working individuals. However, the current strong U.S. economy, combined with welfare-to-work initiatives, has moved adults with both acute and chronic mental illnesses into the workforce, thereby making them ineligible for Medicaid coverage.

This phenomenon has had the unanticipated effect of reducing Medicaid funding for CMHCs without reducing the demand for services. This ironic situation can be summarized as “When the economy is bad, CMHCs that are heavily dependent on Medicaid do better, but when the economy is good, CMHCs suffer.” Obviously, we don’t wish for high unemployment, but the strong economy has had some negative consequences for the centers.

Several other trends are also affecting the fiscal health of CMHCs. As states have become more dependent on Medicaid, they have decreased the amount of general revenue allocated to the support of CMHCs. The downturn in Medicaid funding with no increase in state support has created a lose-lose situation for the centers.

The threat of Medicaid audits or paybacks has led centers that have accurately and ethically billed for Medicaid services in the past to implement corporate compliance plans. These plans formalize internal audit practices and develop internal-exterior

fraud-abuse reporting mechanisms to reduce the risk of paybacks or fines from the Medicaid agency. The real fear that these agencies communicate to staff has in turn led to more careful and conservative billing. Most would agree that the overall impact is underbilling.

CMHCs are often expected to have an open door for charity care and usually do serve poor, uninsured, or underinsured individuals and families for free or on a sliding fee scale. Most CMHCs receive community funding to cover care for these individuals. Managed care companies, sometimes in concert with private providers, refer patients to CMHCs when maximum annual benefit levels are reached. The centers are then faced with even more unfunded patients, placing stress on already tight budgets. In a sense, the money the centers receive from state grants, local government, United Way, and their own fundraising efforts is being used to reinsure both Medicaid and managed care companies.

The number of insured patients with inadequate or no mental health benefits continues to increase. Employers are choosing health plans that manage or limit the number of behavioral health sessions to reduce their premium cost. In the past 11 years, according to the Hay Group (1), behavioral health expenditures as a percentage of the total health care benefit dropped 50 percent, and significantly more health plans have placed limits on all types of mental health care benefits.

These are policy issues that should immediately be evaluated by state mental health authorities throughout the country. CMHCs have traditionally been viewed as a safety-net system for mental health care. We need to ensure that policy makers don’t assume that the safety net is intact because of the general economic good times.

Brian A. Allen, L.C.S.W., M.P.A.

Mr. Allen is president of Mental Health Centers of Central Illinois and vice-president for behavioral health in the Memorial Health System in Springfield, Illinois.

Reference

1. Health Care Plan Design and Cost Trends: 1988 Through 1998. Arlington, Va, National Association of Psychiatric Health Systems and Association of Behavioral Group Practices, 1999

In Defense of NIMH

To the Editor: I usually support Dr. E. Fuller Torrey’s continuing efforts to improve care for patients with serious mental illness, but in his Taking Issue commentary entitled “The ‘New Drugs’ and the Research We Haven’t Done” in the March 2000 issue (1), I think he was being unfair in singling out the National Institute of Mental Health (NIMH) and the Center for Mental Health Services (CMHS) for lack of research on the many issues involved in the care and treatment of these patients.

NIMH has long had an interest in such research. Under the leadership of Dr. Robert Felix, its director from 1946 to 1970, NIMH obtained funding from Congress in 1956 to establish the Hospital Improvement Program grants. It was the first time in the nation’s history that federal monies were made available to public mental hospitals to improve any kind of patient care. The grants supported hundreds of research and demonstration programs of the kind that Dr. Torrey describes. The Fairweather Lodges and Fountain House programs were among the grant recipients. But NIMH could not do the job alone. States still have the primary responsibility for these patients. And where were the researchers in the universities and medical schools?

There is plenty of blame to go around, but, in my view, NIMH did its fair share to stimulate and support better care for patients with serious mental illness.

Lucy D. Ozarin, M.D., M.P.H.

Dr. Ozarin, who is retired, was medical director for the U.S. Public Health Service. She lives in Bethesda, Maryland.

Reference

1. Torrey EF: The “new drugs” and the research we haven’t done. *Psychiatric Services* 51:279, 2000

In Reply: I admire Dr. Ozarin, who was one of the few NIMH staff members in the 1970s and 1980s who was aware of the increasingly obvious failure of deinstitutionalization. But her letter alludes to one source of the problem. When NIMH did make money available for model programs, it was usually done with little or no coordination with the states, or evaluation, or follow-up. Funding for the community mental health centers (CMHCs), for example, specifically bypassed the state mental health agencies. NIMH then did virtually nothing to ensure that the CMHCs provided care for individuals with serious mental illnesses. NIMH acted as a federal Santa Claus but was nowhere in sight a month later when the toys had been broken.

Dr. Ozarin also asks, "Where were the researchers in the universities and medical schools?" In the mid-1970s, NIMH was giving psychiatric training programs more than \$100 million each year with no strings attached. Why didn't NIMH require them to do something for the money?

E. Fuller Torrey, M.D.

Risk of Fatal Heatstroke After Hospitalization

To the Editor: In the August 1998 issue Dr. Nigel Bark (1) reported on a study that found significantly more deaths occurring among patients in state hospitals during heat waves than during control periods. He also reported that hospitalized psychiatric patients had twice the relative risk of dying in a heat wave compared with the general population. The risk was reduced after preventive measures were introduced throughout the state hospital system.

As a corollary to Bark's important findings, we would like to add our observations on the continuing risk of fatal heatstroke immediately after discharge from a psychiatric facility. We have been consulted recently about several cases in which psychotic patients were successfully treated in the hospital during the summer,

only to die unexpectedly from heatstroke within days after discharge. These cases indicated to us that the time after discharge from an extended hospital stay may represent an important but neglected high-risk period for heatstroke.

Patients may be more vulnerable to heatstroke after hospital discharge for several reasons. First, patients who have been noncompliant with their medication before admission have a significantly reduced ability to dissipate heat once antipsychotic and anticholinergic medications are reinstituted during hospitalization (1–5). Second, after recovery, patients may feel more energetic and attempt to compensate for activities they missed while hospitalized. However, most clinicians and patients are unaware of how little physical activity it takes to raise body temperatures to life-threatening levels in a hot, humid environment when heat-loss mechanisms are impaired by drugs. Once sweating ceases under these conditions, a patient who is doing even moderate exercise such as walking briskly may experience a temperature rise exceeding nine degrees Fahrenheit per hour (4).

A third reason for increased vulnerability to heatstroke is that patients who have been sedentary in an air-conditioned hospital environment are neither physically conditioned nor acclimatized to the heat. Acclimatization to heat takes two weeks or more of exposure and requires complex adaptations by the cardiovascular, endocrine, renal, and exocrine systems. Finally, resumption of drug or alcohol use after discharge further increases the risk of heatstroke.

Because of the significant advances cited by Bark in the safe management of acutely ill psychiatric patients on air-conditioned inpatient units, clinicians may be unaware of the dangers of heatstroke among unacclimatized patients after a successful hospital course and discharge. Our clinical experience suggests that it may be worthwhile to investigate the mortality rate of recently discharged psychiatric inpatients spec-

ifically during heat waves. In the interim, clinicians should consider the dangers of hot, humid weather in discharge planning for these patients.

We agree with Dr. Bark that preventive measures are paramount. Although resources are often limited, patients who require assistance should be offered help in obtaining protected housing. Most important, patients, families, and caretakers should be informed about the dangers of heat, humidity, dehydration, and even mild or moderate exertion. In the absence of such precautions, recovered, medicated, and unacclimatized patients, especially those with comorbid medical or addictive disorders, are at high risk of fatal heatstroke if discharged during a heat wave.

Stanley N. Caroff, M.D.

Stephan C. Mann, M.D.

E. Cabrina Campbell, M.D.

The authors are associated with the department of psychiatry at the University of Pennsylvania School of Medicine and the Veterans Affairs Medical Center in Philadelphia.

References

1. Bark N: Deaths of psychiatric patients during heat waves. *Psychiatric Services* 49: 1088–1090, 1998
2. Mann SC, Boger WP: Psychotropic drugs, summer heat and humidity, and hyperpyrexia: a danger restated. *American Journal of Psychiatry* 135:1097–1100, 1978
3. Lazarus A, Mann SC, Caroff SN: *The Neuroleptic Malignant Syndrome and Related Conditions*. Washington, DC, American Psychiatric Press, 1989
4. Knochel JP: Heat stroke and related heat stress disorders. *Disease-a-Month* 35:301–378, 1989
5. Ayd FJ Jr: Fatal hyperpyrexia during chlorpromazine therapy. *Journal of Clinical and Experimental Psychopathology* 17:189–192, 1956