A Psychiatric Case Register for Mental Health Planning

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COMPREHENSIVE community mental health planning is in process in most States as a result of Public Health Service grants-in-aid. This planning entails (*a*) an assessment of needs as to the extent of mental disorders in a community, (*b*) an inventory and evaluation of facilities, programs, and services available for prevention and treatment of such disorders, and (*c*) a determination of what additional facilities or services are needed to better meet the mental health needs of a community.

Incomplete Mental Health Data

No system of continuous data collection has been developed which, to my knowledge, will give reliable estimates of either the incidence or prevalence of mental disorders in a community, be it city, county, or State.

Data on patients in psychiatric hospitals and outpatient facilities systematically collected by the nationwide reporting program of the National Institute of Mental Health, Public Health Service, provide information only on the utilization of such medical care, not on morbidity. These data provide reliable estimates of rates of incidence and prevalence of mental disorders among persons receiving psychiatric care only if overlap in use of psychiatric facilities is minimal.

The pattern of psychiatric services is rapidly changing. The State mental hospital, traditionally isolated functionally and geographically from the community, is no longer the sole resource for treatment of the mentally ill. The trend in mental health is toward community-based and community-oriented services. Psychiatric clinics, general hospitals, and other new types of psychiatric services play an increasingly important role in treatment of the mentally ill. This complex pattern of mental health services requires new approaches to the collection of statistical data for program evaluation and planning.

One approach is to record-link different episodes of illness and services for the same individual over extended periods of time. This record linkage is, in essence, a case register. For this discussion, a psychiatric case register is defined as having two essential features: identification of persons with a mental disorder who live in a specific geographic area and are seen in one or more of a defined set of psychiatric facilities in that area; and maintenance of cumulative statistical records on the psychiatric care these persons receive, along with other pertinent demographic information (*1*).

A case register is a new tool in the field of mental health, although such registers have long been used as research tools in the study of other diseases such as tuberculosis and cancer. Two States, Hawaii and Maryland, have established psychiatric case registers based on reporting from public facilities.

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Maryland has included reporting from private psychiatric facilities, but not from private psychiatric practice, in its reporting system. The University of Rochester in Rochester, N.Y., in 1960 established a psychiatric case register for Monroe County which collates reports from public and private psychiatric facilities; the majority of private psychiatrists in the area have also cooperated in this program. Recently a register operation was initiated for a three-county area in North Carolina. Although not entirely comparable to these four registers, similar studies have been undertaken in San Mateo, Calif.; Dutchess County and Washington Heights, N.Y.; and Martha's Vineyard, Mass.

Based on the experience of the existing registers, a case register is an expensive procedure for data collection even when it is part of an ongoing State system of collecting data from hospitals and outpatient clinics. Use of computers reduces the cost to some extent, but only after the basic programs have been written. Many of the problems of maintaining such a register are yet unsolved.

Unidentified Cases of Disease

Ideally, any case register would contain a complete count of all cases of disease in a community. Such a count, however, can never be achieved for any disease because there are always some unidentified cases. The number of unidentified cases is probably even greater for mental disorders than for other diseases. The question therefore arises as to what the scope of a psychiatric case register should be if it is to be useful and at the same time practical. At the moment it is fairly easy to obtain reports from public facilities. But private facilities and private psychiatry would seem as important a source of information as public psychiatry. The distribution of mental disorders by demographic and social characteristics and the lifetime pattern of disease cannot be adequately studied without data from private psychiatrists. That private psychiatrists are willing to report to a register if given adequate assurance that the information reported will be kept confidential has been demonstrated by the register in Monroe County, N.Y. The American Psychiatric Association has officially endorsed the concept of private reporting to case registers for research purposes. Nevertheless, both the Hawaii and Maryland registers have encountered considerable resistance in their attempts to obtain reports from private psychiatrists. The fact that the Rochester register is based in a university setting rather than a State agency may account for its staff's success in fostering private reporting. The importance of such reporting is illustrated by Monroe County data showing that approximately as many outpatients are seen by private psychiatrists as in psychiatric clinics (*1*). Studies elsewhere have also indicated the importance of including private services in a case register.

Statistical reporting on emotionally disturbed patients by nonpsychiatric physicians would probably be more difficult to achieve on a continuing basis. Moreover the value of such reporting has not been clearly demonstrated. We know that general physicians and internists believe that a large proportion of their patients have emotional problems. Special studies and one-time surveys of general physicians would be useful to provide answers to several questions:

1. What proportion of the mentally ill population is diagnosed and treated for their mental disorders by general physicians and never come into contact with psychiatric services?
2. What particular types of mental health problems do these general physicians diagnose and treat?
3. What is the relationship of mental disorders to other illness?
4. What types of psychiatric assistance do these general physicians consider would be helpful in their treatment and management of such cases?

Many nonmedical community agencies and professional groups also offer a variety of services to the mentally disturbed. Such services include the counseling and special educational programs of schools, casework of family agencies, vocational rehabilitation of the mentally disabled, and personal counseling by ministers. If a case register is confined to a study of persons using psychiatric services, obviously those who use these other resources for help will not be counted. But where is the cutoff point? If

the register is expanded to include other types of service, the extent of emotional and social problems in the population is so great that a register of almost the entire population would be needed. This type of coverage is certainly economically impractical for any large area. Moreover, the variation in knowledge and psychiatric sophistication of nonpsychiatric groups, as evidenced in their varying capabilities in identifying and classifying emotional problems, makes it difficult to assess the value of data from such groups. An alternative to continuous reporting from these groups would be sampling of an agency's caseload for periodic clearance with the register. Such sampling would provide estimates of the proportion of the total agency caseload comprised of persons with prior history of psychiatric illness or who are now receiving psychiatric services and, with periodic followup study, would also afford an estimate of the number who will subsequently be entered in the psychiatric case register during specified periods of time.

Until special studies prove otherwise, it seems reasonable to assume that most, but not all, severe mental disorders eventually come to the attention of the staff of the psychiatric services of a community. Under this assumption I will discuss the uses and limitations of a psychiatric case register for mental health planning.

Unduplicated Counts of Patients

First of all, the register will provide unduplicated counts of persons receiving service at a given moment in time (prevalence). It will also provide an unduplicated count of the number receiving service over a given period of time. Actually, the register is only needed for the second group, since persons rarely receive psychiatric service from more than one facility at the same time. The case registers with which I am familiar use definitions which make it impossible to be under care in two facilities at the same time. For example, arbitrary rules for reporting state that if a private psychiatrist admits a patient to an inpatient facility for short-term hospitalization, the patient must be recorded as terminated from office practice and not recorded as readmitted to office practice until discharged from the hospital, even though the patient is being treated by the same physician while hospitalized.

An erroneous impression of the total number of persons receiving psychiatric service for a given time period is obtained, if admission figures of each facility for that period are simply added together. The Monroe County register data for 1960 indicate an average of two different episodes of psychiatric care per patient during the year; 11 percent of the patients had four or more episodes of service. The reported rate of persons receiving psychiatric service for 1960 would have been 30 per 1,000 based on total admissions, rather than 17 per 1,000 as determined by the register data (*2*).

For planning purposes the unduplicated count of persons receiving psychiatric service is not sufficient. It is necessary to go one step further and determine which subgroups of the total population, classified by such variables as age, sex, race, geographic area, referral source, and diagnosis, are being served by which facilities and which groups are not receiving service. The fact that certain groups do not seek or receive service does not mean that they do not need such service. The register will not indicate why certain groups have higher rates than others. It will only identify these groups for further studies.

A psychiatric case register makes it possible to study the relationship of various groups of patients (classified by age, sex, diagnosis, or other available variables) to a complex network of psychiatric facilities. The register will identify those having had only one episode of service, those who have had repeated episodes of service in the same facility, and those who have been served by several different facilities. In planning services we need to know the expected rate of readmissions for a given facility and the expected rate of subsequent contacts with different services. But the three groups classified by number and variety of contacts should also be examined, using all available data, in an attempt to find out why some persons have only one contact while others have several contacts with one or several types of services. Again, the register alone does not provide the answer, for two reasons. Only those variables recorded for the register reports can be investigated. Also, followup studies on

persons with only one contact are necessary to determine whether they have died or moved from the area and are, therefore, no longer exposed to the risk of readmission to service.

Each item of information collected on persons receiving service should be periodically evaluated on the basis of register experience and other studies. For example, if all available information indicates that such items as birthplace and occupation are not useful discriminators, these items should be eliminated and other more useful data collected. In addition, all registers need procedures to provide for periodic clearance of records on deceased persons and to determine the extent of migration. Both types of clearance are essential in obtaining the correct numerators and denominators for computing rates and for interpretation of longitudinal data.

Evaluation of Programs

The availability of unduplicated counts of the number of individuals receiving service by type of facility as well as the number and variety of contacts for groups will facilitate evaluation of specific psychiatric programs. The success achieved by specific psychiatric facilities in reduction of disability associated with mental illness would be assessed on the basis of patients' subsequent psychiatric experience. Admittedly, the fact that a person has had only one psychiatric contact is a crude measure of treatment success. Detailed followup studies are required to determine which treatment programs should be continued or extended and which should be curtailed or modified.

Case registers can provide the necessary baseline data for evaluating the effect of new programs such as community mental health centers. Examination of admission rates to the State hospitals and the characteristics of patients entering these hospitals before and after initiation of new programs would be one approach to this type of program evaluation. Knowledge of the rates of patient flow between facilities would be useful in predicting not only the need for additional facilities but also the most appropriate staffing patterns for all facilities.

Perhaps more important, the case register as an index of persons who have received psychiatric service provides a sampling frame for studies of the role of genetic, familial, and environmental factors in mental illness, mental retardation, and alcoholism. Determination of the possible causes of these disorders is the first step in learning how and when to establish programs to prevent them.

Studies of Diagnostic Nomenclature

Validity of the diagnostic nomenclature for mental disorders has been openly debated for some time. A case register offers an opportunity to investigate the change or lack of change in diagnosis for a person who has had several psychiatric contacts. In such studies (*3*) the time between contacts must be taken into account, to distinguish between a disagreement in diagnostic classification and an actual change in the patient. Preliminary work (*3*) at the University of Rochester indicated that the usefulness of the current diagnostic classification system for mental disorders varied considerably for the major diagnostic categories. In addition, the pattern of flow of patients through the available psychiatric services could not be ignored. A person's symptoms or degree of symptoms determined to some extent which would be the facility of first contact, although other factors such as age and economic status could not be ignored. The Rochester study revealed that staff reactions to a patient's symptoms varied from one psychiatric service to another and affected the staffs' use of diagnostic labels. The administrative policies of a facility also affected the subsequent disposition of a patient and thus helped determine the facility of second contact.

Among children receiving psychiatric service, the largest proportion are diagnosed as having personality disorders, adjustment reactions, or mental deficiencies, whereas among adults receiving psychiatric service the largest proportion are diagnosed as schizophrenic. Availability of a large number of long-term longitudinal records in a case register will make it possible to determine whether the mental disorders in the children's group and the adult group are of the same type—the difference in diagnoses for the two groups arising from differences in diagnostic criteria—or whether the disorders really represent different types of mental illness.

Frequently, the uses of a case register are described under two primary headings, operational or administrative research and epidemiologic research (*4*). For planning purposes, these two types of research are interrelated. Results of basic epidemiologic research must be used in making administrative decisions, and administrative decisions determine the type of epidemiologic research which is feasible in a given system.

Hawaii's Case Register

The discussion so far has been confined to use of a register for epidemiologic research or in record linkage for individuals. But most case registers are part of a total central reporting system from facilities and therefore provide useful operational or service data for each individual facility, as well. The psychiatric reporting system being developed in Hawaii is based on reports received routinely from the Hawaii State Hospital and the outpatient clinics and programs of the mental health division of the State health department. Recently the mental retardation program and the alcoholism clinic have been incorporated into this register system. Development of the Hawaii register has been the result of a joint effort by the Hawaii Health Department and the Office of Biometry, National Institute of Mental Health. The central statistical reporting system of the State mental health division, started in November 1961 on a pilot basis, became fully operative July 1, 1962. It provides annual tabulations for national reporting to the National Institute of Mental Health and tabulations for the State health department's annual statistical reports. These reports include information on the staff, patients served, and the type and amount of services provided by each facility reporting to the register. Such reports on operations of each facility are essential in evaluating program policies and the effectiveness of service and also aid the administration in long-range planning.

The mental health division of the Hawaii Department of Health is now developing a comprehensive community mental health plan for the State. The planning staff responsible for this 2-year planning process is using all data available in the case register which are appropriate for assessing the mental health needs of the State. In addition, several special studies, such as surveys of general physicians, clergy, and caseloads of social service agencies, will supplement the register data. These special studies will help in assessing the validity of the assumption that most persons in Hawaii with severe mental disorders come in contact with psychiatric facilities.

Conclusion

A psychiatric case register is basically an index of persons coming in contact with psychiatric services. Until all persons with emotional problems seek such service, such a register will not provide the data necessary for computing the incidence and prevalence rates of mental disorders. But each case register will provide longitudinal records of the episodes of illness of a person and of the service he receives for an extended period of time. Without a case register one cannot identify an individual as he enters the network of psychiatric facilities, moves around in it, leaves it, and perhaps re-enters it later. Only a register can provide systematic prospective data on the psychiatric course of patients. The register provides information which, if carefully evaluated, will generate hypotheses and raise questions that will lead to detailed investigations of the history of mental illness and the effectiveness of various types of treatment and services.

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