The Epidemiologic Catchment Area Program of the National Institute of Mental Health

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THE EPIDEMIOLOGIC CATCHMENT AREA (ECA) Program is a developmental series of epidemiologic research studies performed by independent research teams in collaboration with the Center for Epidemiologic Studies (CES) of the Division of Biometry and Epidemiology, National Institute of Mental Health (NIMH). The broad aims of the Program are the historical goals of psychiatric epidemiology, to estimate the incidence and prevalence of mental disorders, to search for etiological clues, and to aid in the planning of health care services and programs. New substantive developments in the field have emphasized the need for specific kinds of data collection, and the methodologies for carrying out psychiatric epidemiologic studies have improved remarkably over the past decade. The ECA studies have built on these developments and methodological studies to provide a framework for a new generation of epidemiologic and health services research in psychiatry.

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Although the ECA Program retains the historical goals of psychiatric epidemiology, the methodologies involved are not in general use. In this paper we discuss five methodological aspects of the ECA Program that together form the basic research design, namely, the emphasis on specific diagnoses, the integration of community surveys with institutional surveys, the collection of prevalence as well as incidence data, the systematic linkage of service utilization data with other epidemiologic variables, and the multisite comparative-collaborative aspect. None of these aspects are totally new to the field, but they have never been combined in this way before, and we therefore believe that data from the ECA Program may address these historical goals in an innovative fashion.

The ECA Program is consonant with NIMH's charge to provide accurate data on the mental health status of the nation. It is also directly responsive to the Center for Epidemiologic Studies' overall goals of stimulating, coordinating, and conducting research on the epidemiology of mental disorders. For several years epidemiologists at NIMH had been calling for the creation of psychiatric epidemiologic field stations similar in some ways to ECA Program sites (*1,2*). The CES had funded two such field stations in 1971, but had not had resources to keep them going. In 1977, however, the President's

Commission on Mental Health (*3*) was established and issued a highly publicized report that focused on the dearth of good epidemiologic data and recommended "immediate efforts to gather reliable data . . . on the incidence of mental health problems and the utilization of mental health services." Although begun slightly before the formation of the Commission, the ECA Program is a major initiative by NIMH in response to this recommendation.

Another stimulating factor has been the increased interest of health professionals in health services research of all kinds, an interest that corresponds closely to NIMH's historical goal of aiding health planning. The health services research field is developing rapidly, probably due at least in part to the increasing costs of health care and the possibility of national health insurance. Within NIMH, the Center for Epidemiologic Studies recently joined the Biometry Division to become the Division of Biometry and Epidemiology. The effect on the ECA Program of this organizational shift was to firmly integrate the etiological emphasis of the CES with the health services research emphasis of the Biometry Division.

Specific Mental Disorders

One difference between the ECA Program and many other recent epidemiologic studies is that it focuses on specific mental disorders instead of on global impairment ratings. Up until the early 1950s, the dominant conceptual framework for psychiatric epidemiology was the medical model, even though social scientists and epidemiologists had been collaborating extensively during and before World War II. For example, specific medical diagnoses were used as dependent variables in most epidemiologic studies up to and including the New Haven study (*4*). But after the war social survey research was established as a practical, accepted technology through the development of multiple-item scaling, accurate and usable survey sampling, and standardized interview training, to name just a few methodologies. Social science researchers also became more aware of the need for assessing the reliability and validity of measurement in all their research, and in psychiatric epidemiology it became clear that diagnoses could not be made with acceptable reliability and validity by using survey technology, or some would say, even in standard clinical practice. Therefore, the field of psychiatric epidemiology switched from specific diagnoses to global scales. This trend began with the Midtown study (*5*) and has continued to the present, with a few exceptions.

The trend toward global mental health ratings satisfied the need of psychiatric epidemiologists to accommodate survey technology, but it was in opposition to many changes in the area of psychiatric classification. Increasingly the available social epidemiologic evidence suggested that different kinds of mental disorders were differentially related to demographic variables like sex, social class, area of residence, and so forth (*6*). There also began to be genetic evidence suggesting that for the different specific diagnoses the degrees of inheritance were different (*7*). And new drugs were discovered that had beneficial effects for specific diagnoses and not for others (*8*). In the areas of classification and diagnosis, operational criteria for diagnoses were developed, along with standardized interview questionnaires and standardized interviewer training techniques, to improve the reliability of diagnosis (*9,10*).

The most important change in the ECA Program has been to focus on specific mental disorders without giving up the interest in rigorous survey methodology. The vehicle to accomplish this end is the NIMH Diagnostic Interview Schedule (DIS), which focuses on specific disorders and takes advantage of the recently developed capabilities in diagnostic assessment (*11*). The DIS makes both current and lifetime diagnoses, with varying definitions of "current," as figure 1 shows. It converts for the first time the methodology of clinical assessment to that of field surveys. The implications of this development for the field of psychiatric epidemiology are rather broad: the conversion not only ties the field into the diagnostic categories on which much laboratory and clinical research is being done (thus aiding in the search for etiological clues); it also ties the field into the diagnostic categories that are used in clinical practice (thus aiding in the planning of mental health facilities).

Figure 1. Diagnostic, symptom, and utilization data obtained in the Epidemiologic Catchment Area (ECA) Program of the National Institute of Mental Health

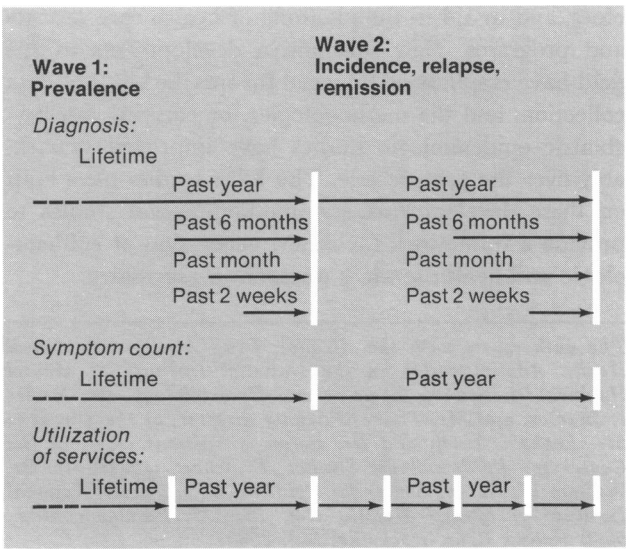
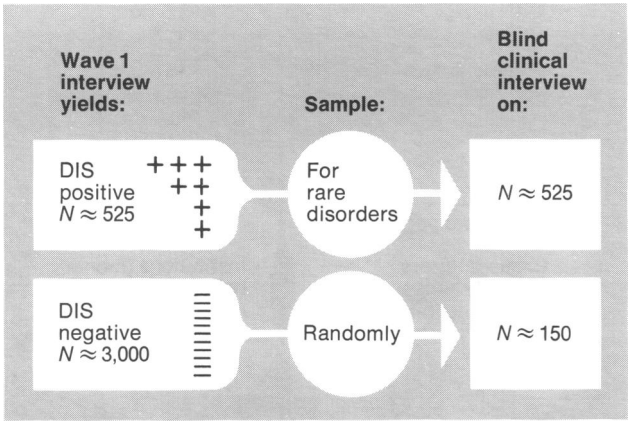


Figure 2. Field validity of the Diagnostic Interview Schedule (DIS) of the National Institute of Mental Health



Part of the ECA Program includes tests of the validity of the DIS. So as to represent all the diagnoses provided by the DIS, the subjects in the first validity study (*12*) were selected according to prior knowledge of their psychiatric condition. The interviewers, however, were not aware of the prior diagnosis or of the diagnosis made by a second interviewer. If the two interviewers had been equivalent in terms of training, this study would have been concerned simply with the reliability of the DIS. However, one of the basic innovations of the DIS is its superimposition of clinical assessment on survey methodology, and this study was designed to test that crossover by having one interviewer be a trained clinical psychiatrist and the other, the kind of interviewer generally found in survey organizations, that is, a person with no clinical training. The high inter-rater agreement that was found gave both good evidence of reliability and evidence that lay interviewers can use the DIS as well as psychiatrists. If the DIS in the hands of a clinical psychiatrist is the criterion, then this study is of criterion validity.

Even if the DIS were found to be valid in a clinical setting, one would still need to address the question of its validity both in the general population, where the frequency of disorder is lower, and under household survey conditions, where the setting is less predictable. A second kind of validity study addresses this need: the false-positive and false-negative rates of the DIS will be assessed in two of the ECA surveys. Within 3 weeks of the survey interviews that are to be conducted as part of the ECA Program, a subsample of people will be interviewed by a psychiatrist using a criterion instrument. An attempt will be made to generate diagnostic heterogeneity by recommending for followup a sample of persons with no disorder according to the DIS interviews and a sample with each of the major disorders, as figure 2 shows. We hope that by following less than a quarter of the samples, we will be able to estimate false-positive and false-negative rates for all disorders with a point prevalence greater than 1 percent. The criterion instrument to be used differs at the two sites of research. At one site it will be the DIS itself in combination with a standardized clinical assessment based on DSM-III (the third revision of the Diagnostic and Statistical Manual of the American Psychiatric Association); at the other site it will be a clinical interview built around the Present State Examination, a structured psychiatric interview widely used around the world.

The requirement for data on specific disorders necessitates a larger sample than is common in psychiatric epidemiologic studies. The sample size for the general population surveys at each site in the ECA Program is set at 4,000 households. If one member of each household is interviewed and we allow for a 75 percent response rate, the yield will be an estimated 3,000 respondents in the general population. The relatively new emphasis on specific mental disorders requires much larger samples than research conducted on global impairment ratings, because of the rarity of the specific disorders. Ten to 20 percent of the general population may have some kind of mental disorder at any given time, but fewer than 5 percent will have any specific disorder, and for many disorders the point prevalence may be closer to 1 percent (*13*). These low frequencies mean that even with a large sample, the yield in cases of disorders is relatively small.

Meeting the goals of the ECA Program entails tasks of estimation (of incidence and prevalence) and analysis (of etiological factors and the factors affecting service utilization). We have projected what the 95 percent confidence intervals for prevalence will be for a total sample and for its subsamples broken down by age, sex, and socioeconomic status in respect to specific disorders having a true population prevalence of 5 percent and 1 percent. For the total sample the interval is from about 4 to 6 percent for a disorder with 5 percent prevalence and from about 0.6 percent to 1.4 percent for a disorder with 1 percent prevalence. When a sample is broken down into subcategories, considerable precision is lost. The interval is adequate for one-way breakdowns by the three demographic variables just mentioned, but it is unacceptable for multivariable analysis of the rare disorders. In terms of the power to analyze the test-specific hypotheses, a sample from one site is barely of adequate size, and for specific disorders it permits the testing of only the simplest and strongest hypotheses (concerning either etiology or health services research). When broader groups of specific mental dis-

orders are considered (for example, affective disorders, all mental disorders, or such variables as the total symptom counts), the power for a sample of this size is much greater.

Community and Institution Surveys

A second aspect of the methodology implemented by the ECA Program is the integration of data from community surveys with data from treatment institutions (fig. 3). The epidemiologist is nearly always faced with this choice of treatment institutions versus community surveys for casefinding; use of both methods simultaneously is rare, and rarer still is the rigorous integration of the two methods. The aim in the ECA Program is to study the total true prevalence of disorders, that is, their prevalence without regard to treatment status.

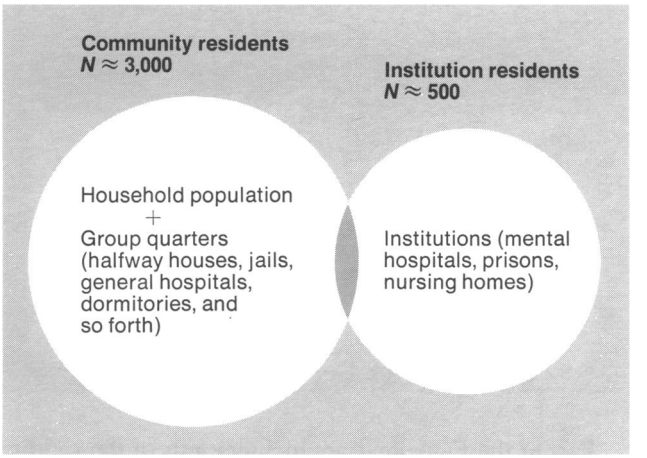
One result of the growth in the social sciences after the war was the realization that many people with bona fide mental disorders never ended up in a treatment setting. The implication was drawn that epidemiologic data based on admissions to treatment were of dubious value for etiological research and for the rational planning of facilities. Epidemiologists and social scientists became aware fairly early of this flaw inherent in treatment data, and both groups began to study in detail the processes by which people with personal problems found their way into the psychiatric treatment system (*14–17*). Later on it became apparent that the majority of people treated for psychiatric problems were treated in the general health care sector, not in the psychiatric sector (*18,19*). The fact that data on psychiatric problems were not routinely collected in general health care facilities only emphasized the difficulty of studying the total true prevalence of mental disorders.

This problem of total true prevalence is confounded with that of case identification, which we have already discussed. In early studies through the one by Hollingshead and Redlich (*4*), treatment agencies were used to find cases, and since treatment agencies routinely make a diagnosis, these studies had data on specific disorders. The dissatisfaction with data on treated cases was one reason for shifting to field surveys, but this shift entailed a loss of data on specific mental disorders. Some researchers decided to completely ignore psychiatric epidemiologic research that relied on studies of treated cases, as did the Dohrenwends in their classic review (*20*). If in examining the body of research from community studies, one attempts to look at community prevalence data for specific diagnoses instead of at the more global "psychological disorders," the number of pertinent studies drops sharply.

The degree to which persons with psychiatric disorders are treated varies by specific diagnosis. After an intensive search for schizophrenic cases in Detroit, Dunham concluded that "virtually all schizophrenics are eventually hospitalized" (*21*). In a study in rural Sweden, 12 psychotics were located through a combination of casefinding techniques; all 12 had been seen by a physician (*22*), 11 of them by a psychiatrist. These lamentably scanty data suggest that most psychotics end up in some sort of psychiatric treatment, although there are exceptions in some rural societies or premodern societies such as the Hutterites (*23*). For nonpsychotic disorders, the proportion treated is likely to be much lower. Data from treatment institutions probably include a higher proportion of the total population of schizophrenics than do community data. However, since the majority of depressive disorders are probably not treated, community data are more accurate for this diagnosis. The upshot of these considerations is that data solely from community surveys are also inaccurate because they miss people with severe mental disorders who are in treatment. Thus, one requirement of the ECA Program has been the integration of community surveys with surveys of treatment institutions.

There is considerable variation in the rates of mental disorder cited in research studies for different areas, part of which results from the fact that psychiatrically disordered persons select themselves into certain areas (*24*). Some of this selection process is related to the presence of institutions in given areas. For example, differences in the rates for mental disorder between urban and rural areas probably result largely from the greater availability of facilities in uban areas. In comparing results from two research studies (or two ECA sites), one would prefer that the greater availability of facilities in one area made no difference; in a broad sense, this sort of difference is measurement error. Pay-

Figure 3. Coordination of community and institution surveys in the Epidemiologic Catchment Area Program of the National Institute of Mental Health



ing careful attention to the definition of residence can minimize this source of error. We do this by establishing mutually exclusive and exhaustive definitions of residence so that subjects will be picked up in one, and only one, of the two kinds of surveys (institutional or general population), and their geographic area of residence will be unambiguously established.

In the ECA Program, the sites for research are areas that were previously designated as Community Mental Health Center (CMHC) catchment areas, from which the name of the Program itself comes. These are geographic areas with populations of 75,000 to 250,000. Since, however, to insure a large enough population base for the sample survey, the Program requires an area with a minimum population size of 200,000, in some cases CMHC catchment areas must be combined to form the basic geographic unit of study. These catchment areas (and combinations thereof) were chosen because it has been argued that they are the best geographic units for assessing the supply of mental health resources (*25*). The ECA research will contribute to an assessment of the demand for these resources in geographic units for which data on the supply of resources are available. This potential linkup of the supply and demand for a given area is an important benefit of the ECA Program. We have specific rules for determining when a person is and is not considered a resident of a CMHC area. The U.S. Census defines three broad categories of living arrangements: a household, a group quarter, or an institution (*26*). Psychiatric hospitals, extended care facilities (such as homes for the aged), and prisons are sampled in the survey of treatment institutions. The residence for persons in treatment institutions is defined by their residence upon admission to the institution. Group quarters are transient residences like flophouses and YMCAs, but the category also includes halfway houses, college dormitories, military barracks, and general hospitals. Group quarters are sampled in the general population survey in two ways: either by listing the residential unit as a dwelling unit and surveying it as usual (the procedure used, for example, for YMCAs and flophouses) or by inquiring just before the household interview about other members of the household who are absent and following them into the group quarters for an interview if necessary (the procedure used, for example, for college dormitories and general hospitals). In the second instance, the relevant group quarters are not included in the community survey, since residence is defined by the person's household address.

We expect the difference in the total true prevalence rate between the several ECA sites to be much smaller than differences between either institution rates or community rates between sites. Knowledge of the sizes of these differences will be helpful in interpreting differences between various past studies, between various sociodemographic groups, and between the ECA sites.

The sample size for the survey of treatment institutions has been tentatively set at 500. For most catchment areas, sampling at the same fraction as in the general population would yield an institutional sample of about 50. However, the prevalence rate in institutions is much higher than in the general population. Sampling theory suggests that in this situation, it is cost efficient to oversample this stratum: the result is a more precise estimate of the total true prevalence rate (*27*). As well as increasing the precision for the total rate, a sample size of 500 will yield rough estimates of the overall rate of mental disorders within each of the three major kinds of institutions (mental hospitals, homes for the aged, and prisons).

Incidence and Prevalence Data

Another methodological aspect of the ECA Program is its emphasis on incidence. Incidence rates are superior to prevalence rates for the study of etiology. For diseases that are often fatal (for example, heart disease or cancer), the more important advantage of the incidence rate is that it is not contaminated by mortality; for chronic, nonfatal diseases (for example, diabetes and mental disorders), the more important advantage is that incidence rates are less contaminated by insidious onset and secondary complications. Mental disorders develop over extended periods, and a person's diagnosis and the severity of his or her disorder may shift from time to time in as yet unknown ways. Since the incidence rate gives the investigator the least contaminated look at the disorder, etiological relationships should become more visible. If there is a precipitating event, the investigator should be able to discern it much more easily than if it occurred in the distant past. Incidence rates and etiological relationships are relevant to programs of primary prevention, but for the planning of services and programs, prevalence rates are superior because they are closer to an estimate of the demand for treatment.

Incidence rates require the identification of new cases, and in effect this means monitoring a population for a period. In the past the closest approximation to incidence has come from statistics on admissions to treatment, in which new cases are those without prior treatment; that is, in effect, the treatment system monitors the population continuously. However, monitoring a population for a period is much more costly when psychiatric treatment is not the criterion for casefinding, and therefore in most community studies, prevalence

rates are estimated. The irony is that even though incidence data are much more relevant to etiology than prevalence data, as we have noted, community surveys are usually conducted by investigators interested in etiology.

The ECA Program requires two waves of interviews with the same persons in both the community and the institution surveys. Two waves are the minimum number required for identification of new cases, and furthermore this two-wave design allows the study of relapse and readmission (fig. 1).

Linkage With Service Utilization Data

Another fundamental innovation in the ECA Program is its provision for the systematic collection of survey data from people about their use of psychiatric, general health, and other human services (fig. 1). One goal of the Program is to determine why people use or do not use treatment facilities. Thus, the objective is to ascertain how unmet need is generated and why some groups are underserved. The strategy is to analyze differences between the psychiatrically disordered persons who are in treatment and those with the same diagnoses who are not. Groups that include many people who meet the criteria for diagnosis but are not in treatment are "underserved" (*3*); areas where there are many such persons may need new treatment facilities. We suspect that two kinds of factors may be important here: (*a*) barriers to care, which include aspects of mental health services and programs that hinder treatment (such as long waiting times for appointments, long distances to treatment facilities, inadequate or understaffed facilities, the cost of care, and so forth) and (*b*) illness behavior, which includes the person's ability and willingness to identify his or her psychiatric problems, attitudes toward help-seeking in general, and avoidance of psychiatric treatment due to its stigma. In the first wave of interviews, factors that are associated with barriers to care, with illness behavior, or with both, can be identified in the data analysis and can then be used prospectively to predict utilization over the coming year.

A related goal of the ECA Program is to discover how people choose the specific locus of treatment and to assess the degree to which facilities are used appropriately. To enable us to understand better the pathways leading into the various kinds of services, utilization data will include the specialty mental health sector as well as the general health care sector and the nonhealth sector. By covering a broad range of facilities and having diagnostic data available, we can study issues related to duplication of services, inappropriate provision of services, and the use of multiple facilities for a single clinical episode—analyses that have major policy implications for the financing and operation of the mental health service system. This sort of data base is much stronger than the earlier case registers, which relied solely on treated cases (*28*).

Multisite Aspect of ECA

The ECA Program is designed to have several different sites of research. The program plan is tentative and depends on results from early sites, response from the field, special research opportunities that may present themselves, and the availability of funds. The Program is designed to complement the psychiatric component of a large-scale national sample survey such as the Health Examination Survey of the National Center for Health Statistics. Even though only a large-scale project such as the Health Examination Survey can provide nationwide estimates of prevalence, a multisite design such as the ECA Program has many advantages over a large single-shot survey. The major advantage is that it permits results from many sites of research to be compared. In the past there has been considerable disparity in results from different research, due, it is suspected, to the different orientations and methodologies of the investigators (*20*). This disparity has led some researchers to become pessimistic about the possibility of ever obtaining the replicable results that are so necessary if we are to build a scientific foundation for the field of psychiatric epidemiology. Our hope in this project is to demonstrate which results are replicable and which depend on the specific research site. The results that occur repeatedly can contribute to the desired scientific foundation; the results that are observed at only one site or at only a few sites may provide etiological leads if methodological differences are examined and ruled out. Under certain conditions, data from several sites can be pooled for analysis of rare disorders (*29–31*).

In the field of psychiatric epidemiology, a multisite design probably generates higher quality data than the large one-shot survey. To integrate a general population survey with an institutional survey on a national level is extremely difficult. Both the Census Bureau and the National Center for Health Statistics conduct their surveys of institutions separately from their general populaton surveys because of this difficulty. To integrate the two surveys as carefully as is necessary requires intimate knowledge of local institutions and the populations that they treat. Coordinating the two surveys requires the explicit cooperation of each institution in the area, which is difficult to obtain in a large-scale national effort. Furthermore, smaller, local sites of research allow considerably more involvement of high-level, professional researchers in the actual survey process than is usual for typical sample surveys. And participation of

such researchers not only increases the probability of obtaining high-quality data, but also should alert us quickly to shortcomings in the DIS or in the quality control process.

Summary

We hope that the ECA Program can make a significant, and perhaps unique, contribution to the field of psychiatric epidemiology and to mental health services research. If the Program provides total true prevalence data on mental disorders according to the latest diagnostic criteria, that in itself will be a significant contribution. Such data should be of enormous benefit to those interested in etiology as well as those interested in health services research. For researchers interested in etiology, the data can be used to identify, by comparison, high-risk groups; for those interested in health services research, the results can serve as a health planning guide that does not depend on the presence or absence of treatment facilities in a given area.

Incidence data will be the second major contribution of the ECA Program. Its two-wave design enhances the study of incidence, etiology, and the natural history of disorders and also allows study of the social behavior of persons entering treatment for mental disorders—a subject important to health planners.

Finally, a significant result of the ECA Program may be the establishment of a viable standardized methodology for the epidemiologic study of mental disorders by means of which demonstrably replicable results can be produced. Once we demonstrate the equivalence of method and results, then the stage is set for comparative studies of all sorts.

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