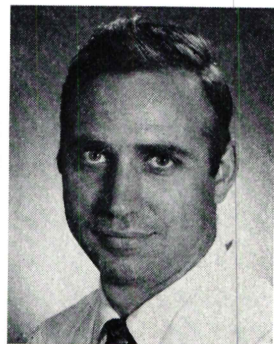


The Community as an Epidemiological Laboratory



Irving I. Kessler

Introduktion och sammanfattning

Liksom socialvetenskaperna kan de medicinska epidemiologerna uppfatta samhället som ett slags laboratorium, där man kan samla in data om hälso- och sjukvårdsfenomen under kontrollerade betingelser. Inom samhällsvetenskaperna har en systematisk forskning med sådan inriktning förekommit ända sedan 1700-talet. På senare år har också ett relativt stort antal samhällsstudier med en socialmedicinsk inriktning kommit till stånd. Ett stort antal samhällen, landsbygdsområden, små- och storstadsområden har utforskats i en rad olika avseenden under de mest skiftande metodologiska förhållanden. Vissa studier har gällt hela samhällen, andra har avsett utvalda stickprovsgrupper.

I nedanstående artikel — författad av Irving I. Kessler, bitr. professor vid School of Hygiene and Public Health, Johns Hopkins University, Baltimore, USA — lämnas en översikt över de principiella problem som möter när man skall försöka använda samhället som ett "socialmedicinskt laboratorium".

Artikeln beaktar härvid tre huvudaspekter.

För det första: Vilka kriterier skall man ha när det gäller att välja "rätt samhälle" för en forskningsuppgift?

För det andra: Hur skall en sådan "socialmedicinsk laboratoriestudie" planeras?

För det tredje: Vilka kriterier blir aktuella, när det gäller att värdera resultatet av sådana samhällsstudier?

Medical practitioners are interested directly in the health of their patients, but only indirectly in the health of their communities, which is the legally defined responsibility of public officials. In addition to the latter, two other scientific groups are concerned with community patterns of health and disease, viz. the social scientists and the medical epidemiologists. To these researchers the community is akin to a laboratory where data on health-related phenomena may be collected under controlled conditions.

The systematic collection of data relating to defined populations has its roots in the social survey movement of the eighteenth and nineteenth centuries beginning, perhaps, with the studies of conditions within English and Welsh prisons by John Howard¹¹. The increasingly sophisticated studies on life in the laboring classes by Le Play¹⁵, Booth² and Rountree¹⁸ encouraged the establishment of the first settlements for community studies in Chicago's Hull House¹ and in Boston's South End House²². With the establishment of the Russell Sage Foundation in 1906 and its sponsorship of the Pittsburgh Survey¹² the modern era of the scientific, sociologic study of communities may be said to have begun.

The pioneering social surveys of the last century have their epidemiological counterpart in the sanitary surveys of that era, the most significant being those of Chadwick⁴ in London and Shattuck¹⁹ in Boston. These were primarily descriptive, rather than analytic, in design. The statistical methods which underlie modern epidemiologic research owe their development to such workers as Graunt¹⁰ and Farr⁵ as well as to the founders of mathematical biostatistics, including Galton⁹, Pearson¹⁷ and Fisher⁶. The patterns and problems of life in the urban environment have increasingly engaged the attention of social scientists since Robert E. Park first described "the city as a social laboratory"²⁰. Today there are not only individual researchers but entire institutes and academic centers devoted to urban studies. All facets of urban living have come under scrutiny: health, poverty, environmental pollution, education, habitation, transportation, and the interactions of these factors with each other as well as with other variables of interest.

For epidemiologists, by way of contrast, communities are not of primary interest in and of themselves. Their concerns are mainly with elucidating pathogenetic mechanisms: identifying risk factors in disease and, to the extent possible, etiologic agents. However, the scientific method requires that epidemiologic investigations be conducted on subjects selected from well-defined "denominator" populations in order to enhance the validity of the inferences which may be drawn from the calculated statistics.

Study populations may be selected from groups of hospitalized patients. In such instances, cases identified as having a particular disease or characteristic are compared, in relation to a variable of interest, with "control" patients free of the disease or characteristic under study. Alternatively, cases and controls may be obtained from rosters of industrial workers, labor union members, school classes, insurance holders, military veterans, death certificates and the like.

Another possibility is the community-based sample or study population. Panum's¹⁶ study of measles in the Faroe Islands and Snow's²¹ obser-

vations on cholera in London illustrate one application of this methodologic approach, viz, the investigation of a disease where it is epidemic or highly prevalent. In recent years, a relatively large number of community studies have been undertaken in the Western Hemisphere. A wide variety of communities, rural, urban and metropolitan have undergone investigation. Just as diverse have been the study objectives: some being concerned with all recognizable diseases, and others with selected conditions, medical, psychiatric or social. Methods have included the use of private censuses, personal interviews, mailed questionnaires, direct observations, physical or screening examinations and reviews of existing medical and vital data. In some studies the entire community was surveyed while in others, sampling procedures of various sorts were employed. In the remainder of this paper, it is proposed to suggest first, some factors to be considered in selecting a community; second, various types of study design and, finally, criteria for the evaluation of community studies. A critical review of ongoing and completed studies is to appear elsewhere¹³.

Choice of a Community

The choice of a community for study must, at least in part, be a function of the study objectives. If one is interested in a particular disease, for example, then one might select a community in which the reported prevalence of the disease is high. This would assure an adequate number of cases for statistical analysis. Equally important, the chances of identifying risk factors or etiologic agents would be enhanced since the prevalence of these should parallel that of the disease itself. The elucidation of the pathogenesis of a disease may also require studies in communities of unusually low disease prevalence, where exposure to risk factors may be diminished or immunity is increased. In fact, if a suitable degree of coordination between laboratories could be accomplished, it might be feasible to establish two companion population studies: one in a community of high prevalence and the other in an otherwise comparable

community of low prevalence. Another possibility might be the selection of a "control" community to serve for a comparison of outcomes with a study community. This would control for the effects of the study procedures themselves upon ascertainment of disease or other characteristic of interest.

If many diseases or risk factors are to be investigated simultaneously, a sizable and heterogeneous community is needed, especially if relatively infrequent conditions are of interest. A number of advantages and disadvantages are inherent in large community studies. Medical and scientific resources are usually close by and the recruitment and maintenance of trained personnel is facilitated. On the other hand, the costs of operating population laboratories are often higher in metropolitan cities and greater efforts are required to maintain favorable public relations. By the same token, it is sometimes difficult to attract suitably trained research personnel to small communities and it may be impossible to justify the expense of establishing clinical and laboratory facilities which are to be employed only for the duration of the study. A peculiarity of some studies, to which the small community may be especially prone, is the "Hawthorne effect". By this is meant the effect upon subjects of the knowledge that they are taking part in an experiment of some sort. Tecumseh, Michigan⁷, for example, is a small town of 10,000 in which a comprehensive population laboratory has been established. All residents have undergone periodic interview and examination for a number of years. One can conceive of ways in which the responses and health behavior of this intensively studied community might be affected by the research facility in its midst. The use of a "control" community, mentioned above, would obviate this potential problem.

A useful, though not essential, factor in choosing a community for study is the availability of existing demographic data relating to it. Prior knowledge of the distribution of the population according to such variables as age, sex, occupation and education will facilitate the choice of appropriate sampling methods, stratification schemes

and so forth. This information can be obtained ad hoc as well, though at additional cost.

Finally, there are circumstances in which a community may be chosen for study although it fails to satisfy any of the above criteria. Primarily these arise when substantive data on a particular community are needed for public health, as opposed to epidemiological, purposes. In this case, the interest lies not so much in disease etiology as in the identification of unmet health needs and other problem areas.

To summarize, six criteria have been suggested for selecting a community:

1. Unusual prevalence of disease
2. Unusual prevalence of suspected risk factor
3. Administrative convenience
4. Favorable community relations
5. Availability of demographic data on the community
6. Need for substantive data on the community

In considering the optimal size of a community for study, four criteria are recommended:

1. The nature of the problems to be investigated
2. Whether total ascertainment or sampling is proposed
3. The confidence level and power of statistical test to be employed
4. The capacity of the study staff to collect and analyse the data

Types of Study Design

Many population laboratories, especially the relatively permanent ones, utilize the prospective approach. All residents of a community, or a statistically selected sample thereof, are identified at a point in time, interviewed and, perhaps, examined. Thereafter, efforts are made to ascertain all important events of medical significance occurring to members of the "cohort". If ascertainment of such events is complete and accurate, then the true risks of disease morbidity or mortality can be measured in groups of people who share relevant characteristics in common. For example, a two-thirds sample of adults residing in Framingham, Massachusetts, has been followed for over

twenty years and their blood pressure changes measured over time⁸. By determining the incidence of coronary heart disease in this cohort it has become possible to correlate initial and subsequent blood pressure levels with ultimate risk of coronary disease. In this manner, a new risk factor of disease has been identified.

Some investigators believe that the prospective approach increases the likelihood of generating new etiological hypotheses. This view stems from a unique characteristic of longitudinal studies: that, among the subjects being examined, there are some who are or will soon be in the developmental stages of their disease. With the exception of the most prevalent conditions, however, relatively few cases of particular diseases can be expected to develop in cohorts of the usual size during the usual periods of observation. A population of 10,000 Americans followed for one year would yield no more than 2 cases of stomach cancer, for example. Another difficulty in prospective studies is that of case follow-up. In no epidemiologic studies is it easy to persuade all subjects to cooperate; in prospective studies the investigator must continually expose himself to the risk of non-response. Consequently, all prospective studies suffer from attrition of the cohort through non-response as well as through migration and death. The costs of minimizing such losses is high and, sometimes, not easily justified to funding agencies. As a result, nonresponding or migrating subjects are ignored in some community studies; in others, unduly modest efforts are made to trace them. The extent of the effort to reduce nonresponse is, perhaps, the hallmark of the well-executed prospective community study.

Most community studies are not prospective but, rather, cross-sectional in design. As such, they are characterized by measurements of health parameters at a given point or over a relatively short period of time. The resulting data pertain to the prevalence rather than the incidence of disease. The distinction between these two statistics is important to the epidemiologist who is basically interested in disease etiology. Prevalence is a function of both incidence and duration of di-

sease over time. Prevalent cases of cervical cancer, for example, would tend to be older than newly incident cases. More importantly, the environmental factors to which the prevalent cases have been exposed since the onset of their disease can be mistaken for antecedent (and, therefore, possibly etiologic) factors.

Cross-sectional community studies are often made necessary by the difficulties in obtaining long-term funds for prospective investigations. It is easier to propose a one- or two-year study to test a specific hypothesis than to justify an expensive 10-year search for risk factors which may or may not be discovered. As a matter of fact, this has the advantages of encouraging the investigator to clarify his objectives and to complete his work in a reasonable time. Prospective studies often leave one with the difficult problem of deciding when they have outlived their scientific usefulness.

It is sometimes possible to combine advantageous features of both the prospective and the cross-sectional approaches. For example, the study design of the Rhode Island Population Research Laboratory incorporates a clustered community sample with five successive annual surveys⁹. Each survey will yield prevalence data for the particular year, but comparisons between the results for successive years will provide longitudinal data.

Very few community studies are of the retrospective type, in which existing medical records alone are utilized. A rather unique example of this is the epidemiological study center in Rochester, Minnesota¹⁴. This community of some 50,000 persons is served by the Mayo Clinic and by several other institutions affiliated with it, all of which share a central medical record system. Since the pattern of medical care in Rochester is centripetal, an essentially complete record of the population's morbidity is to be found in the central record file. This has made it feasible to conduct a number of community health surveys with the existing data rather than by cross-sectional or prospective survey.

It must be noted, however, that in many com-

munities the patterns of seeking medical care are not centripetal but centrifugal or diffuse, thus making it unwise to depend upon local hospital records for investigational purposes. Moreover, the retrospective approach would not be suitable for the study of conditions which do not invariably lead to hospitalization or clinic visit. It must also be limited to variables of interest which are routinely entered in the medical record: appendectomy history, circumcision status, detailed smoking habits and similar items are generally not recorded in hospital charts in the United States.

Criteria for Evaluation

Evaluations of community studies should be in terms of their stated objectives. For studies undertaken in the hope of generating new hypotheses, the number and quality of such hypotheses may provide a benchmark. However, the failure of a study to generate a new hypothesis is not, per se, grounds for its dismissal. Negative findings are often valuable, provided that they result from well-designed and well-executed procedures.

Studies conducted for the purpose of testing an existing etiological hypothesis can also be valuable. A single prospective study may obviate the need for several retrospective (case-control) studies which, together, may equal or exceed its cost. The prospective study also provides a measure of the *actual* risk of disease in contrast with the *relative* risk estimates deriving from retrospective studies.*

A negative criterion for the evaluation of community studies is the volume of data collected but remaining unanalyzed after a reasonable length of time. This can be a problem with large prospective community surveys in which study objectives have been imprecisely defined and in which, consequently, little discrimination between the scientific "claff and wheat" has been exercised. It is, of course, true that some use can almost always be found for unanalyzed data; for example, in the classroom. However, the relatively high cost

of community studies is not consistent with such use of data.

Community studies undertaken for applied, rather than scientific, public health purposes are, almost by definition, valuable to the community. By contrast, the direct value to the community of scientifically oriented epidemiological surveys is limited: these are designed to study diseases, rather than diseased community residents. This distinction assumes importance to the degree that the cooperation and responsiveness of the community is required for a study's completion. It suggests a technical criterion for the evaluation of community studies, viz. the nonresponse rate. A related criterion would be the extent to which outmigrants and other nonrespondents are followed in order to secure relevant information about them. As a final, technical, criterion of methodological quality we can suggest the method employed by the investigators to obtain an independent validation of patient responses given at the personal interview.

The major criteria suggested for the evaluation of community studies may be summarized as follows:

General Criteria:

1. productivity in generating new hypotheses
2. productivity in testing old hypotheses
3. direct utility to the community
4. volume of collected, but unanalysed, data

Technical Criteria:

1. nonresponse rates
2. followup of outmigrants and nonrespondents
3. independent validation of responses

Conclusions

For population laboratories to fully realize their potential, a number of conditions should be satisfied. The first, and most obvious, is an *appropriate choice of the community*. Administrative convenience is not unimportant, but the methodologic suitability of a specific community for a specific study must not be ignored. To accomplish this, all available information on the medical, environmental and socio-economic attributes of

* Direct estimates of risk can also be derived from retrospective studies if the entire community is studied.

the community should be examined. Community studies sometimes disregard the distinguishing features of the communities per se as variables of importance. To remedy this, close collaboration between epidemiologists and sociologists is suggested, in order that due consideration be accorded all relevant community characteristics in future studies.

A second condition concerns the *objectives of the study*. These should be specified in advance and as precisely as possible. If large amounts of descriptive data are to be collected in order to confirm the results of other studies, this can often be efficiently and economically combined with the statistical testing of specific etiologic hypotheses.

The *use of control communities* is also suggested. One type of control community, in which outcome is measured but in which no manipulation by interview or examination takes place, may make it possible to control for the effects of the study procedures independently of the study variables. The effect of a community characteristic (for example, air pollution) may be studied by using another type of control community, one in which the characteristic is lacking.

A high degree of *coordination between community laboratories*, especially in regard to methods and operational definitions, is very desirable. This will not only eliminate unnecessary duplications of effort, but will also permit meaningful comparisons to be drawn between findings in the various studies.

Collaboration with local public health departments and other sources of data on morbidity, mortality and demography will often make it possible to obtain an independent validation of questionnaire responses and other study findings. The laboratory, in turn, may be of service to the public health agencies, by conduction evaluations of various ongoing programs, for example.

A final desideratum for community studies should be a mechanism, preferably built-in, for *periodic evaluation* with a view to possible modification or even termination. The procedure should seek to determine whether the objectives are as

relevant as they were at the study's inception and whether changes in emphasis or in design are indicated by new advances in knowledge.

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Symposium för psykiatrisk yrkesrehabilitering i Örebro

I samråd med Svenska psykiatriska föreningen och Svenska föreningen för psykisk hälsovård anordnas i samarbete med Örebro läns landsting och regionsjukhuset i Örebro genom psykiatriska rehabiliteringskliniken ett symposium för psykiatrisk yrkesrehabilitering under tiden 8—10 april 1970.

Föredragshållare:

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Byråchef A Berg, Stockholm
Socionom I Berkvist, Örebro
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Plats: Regionsjukhuset i Örebro, NP-blockets föreläsningssal

Deltagare: Alla personalgrupper inom rehabiliteringsteam samt personal från försäkringskassa, arbetsvård och socialvård inbjudes. Symposiet är **kostnadsfritt**. Resor och uppehälle betalas av deltagarna. Rum förmedlas genom arrangören.

Anmälan om deltagande: Med uppgift om tjänstgöringsbefattning och -plats till överläkare, dr Siegfried Rost, psykiatriska rehabiliteringskliniken, Regionsjukhuset, 700 04 Örebro 4 (019/13 02 00)

Anmälan senast: 25 mars

Max deltagarantal: 100



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