

*There are many opportunities for productive epidemiologic research in hospitals. This paper outlines the potentials as well as the limitations of such studies in hospitals. Finally, emphasis is placed on collaboration between epidemiologic analysis, clinical study, and laboratory investigation.*

## **POTENTIAL USES AND LIMITATIONS OF HOSPITAL DATA IN EPIDEMIOLOGIC RESEARCH**

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**E**PIDEMIOLOGICAL investigation in hospitals is not new. In the past its use has been discouraged by those who maintained that the data would not be sufficiently representative to be of research value. The passage of time and experience have shed doubt on this attitude; and numerous examples of the value of epidemiology in hospitals can now be found in the literature. As hospitals have grown in importance with respect to the medical needs of communities, they have also become more valuable resources for the epidemiologic study of disease in populations.

### **A Definition of "Epidemiology in Hospitals"**

"Epidemiology in Hospitals" may be defined as any investigation relating cases identified in hospitals to a population obtained from either these same hospitals or a definable community served by these hospitals. The purpose is to discover attributes associated with the cases or the frequency and distribution of the cases which may lead to a better understanding of the cause and prevention of these conditions.

This definition implies two types of

studies, depending on whether the population at risk (the denominator population) or the control group is derived from within hospitals or from the community at large. The cases (the numerator population) are by definition detected within hospitals. Type I studies, "Epidemiology within Hospitals," are restricted to cases and controls drawn from one or more institutions. Type II studies, "Community-wide Hospital Epidemiology," usually involves those cases which are drawn from all hospitals serving a community and which can be related to a geographically defined community population.

My definition is admittedly broad; but it is defensible on the basis of the fundamental operations in epidemiology—namely, relating case populations to "at risk" or control populations. This session on "Epidemiology in Hospitals" further bears out this viewpoint, as evidenced by the wide range of epidemiologic studies which can be performed in hospitals. The papers presented extended from clinical research to hospital administration and even to community action.

This paper will be confined mainly to inpatient hospital studies. The same

**Table 1—Epidemiology in Hospitals**

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Potential Uses

Possible Type I Studies (Epidemiology within Hospitals)

1. To study disease resulting from hospitalization
2. To study the natural history of a disease
3. To study attributes associated with disease
4. To study associations between diseases
5. To facilitate cooperative experimental, clinical, and epidemiologic studies

Possible Type II Studies (Community-wide Hospital Epidemiology)

1. To determine disease morbidity
2. To describe demographic and geographic patterns of disease
3. To identify instances of familial occurrence of disease
4. To facilitate comparative study of hospital and death certificate indexing of causes of death
5. To study administrative planning

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principles apply to outpatient investigations except that good diagnostic indexes are not usually kept on outpatients. Various health insurance plans, such as the Health Insurance Plan of Greater New York and the Kaiser Foundation Health Plan, have highly efficient diagnostic indexing of outpatient as well as inpatient services; and these records have been used for research purposes.<sup>1-3</sup>

Type I Studies: "Epidemiology within Hospitals"—The studies included in this category have not ordinarily been considered epidemiologic. The analytic technics utilized, however, are entirely analogous to those in epidemiology. They involve populations of cases rather than individual patients; and they embody a comparison of those cases with either a population at risk or with a control population. Such methods are employed most obviously in studies of illness resulting from hospitalization, e.g., hospital-acquired infections,<sup>4</sup> adverse effects of drugs,<sup>5</sup> and delayed effects of

medical treatment such as x-ray exposure.<sup>6,7</sup>

Epidemiologic methods can be applied to hospital data to study the natural history of disease after a certain stage of diagnosis. For example, do any important personal, physiological, or environmental factors affect prognosis in cancer? To investigate such possibilities, one may do a case-control study comparing a population of cancer cases with attribute X to another population of cancer patients without the X attribute.<sup>8</sup> One may also apply life-table methods to hospital data to study the prognosis of a rare disorder such as systemic lupus erythematosus, as was done by Merrell and Shulman.<sup>9</sup> Patients identified in a hospital with an abnormal laboratory test, e.g., a chronic biologic false-positive Wasserman test<sup>10</sup> or a positive L.E.-cell test,<sup>11</sup> are being followed to determine the disease implications of such abnormal tests.

Hospital data can yield important clues as to whether particular attributes are associated with disease. For example, cigarette smoking associated with lung cancer was first suspected from hospital studies. The validity and the magnitude of this association was then confirmed by larger and more carefully controlled population studies.<sup>12</sup> Mantel and Haenszel cite many retrospective studies of cancer in which hospitalized cases and matched controls have been used in search of attributes associated with disease.<sup>13</sup> Many such studies have come from the Roswell Park Memorial Institute, partly because of its policy of administering routinely a comprehensive, general purpose interview to all patients admitted. Some respondents with an initial diagnosis of cancer may be found subsequently not to have such a diagnosis. These patients have been used effectively as controls for those with a documented diagnosis of cancer.

Analogously, hospital data can be used to study associations between dis-

eases.<sup>14</sup> This may be hazardous, however, because the associated disease is likely to be a selective factor for admission to hospital<sup>15</sup>; and the most careful choice of a control group will be required.

An example of a cooperative experimental, clinical, and epidemiologic study conducted in a hospital is that of Chalmers and his co-workers on the effects of diet, rest, and physical reconditioning on patients with acute hepatitis.<sup>16</sup> These authors, including one epidemiologist (W.E.R.), randomly assigned acute hepatitis patients to various hospital wards which differed essentially only in the types of treatment administered. Statistical testing showed that the patients were adequately randomized in terms of their personal characteristics and objective measures of the severity of their disease. In addition to the valuable information derived from the original short-term study, Dr. Chalmers has now completed a ten-year follow-up of most of the original hepatitis patients in comparison with a control group to study the frequency of residual effects of hepatitis according to the different types of treatment.<sup>16a</sup>

Type II Studies: "Community-wide Hospital Epidemiology" — Community-wide hospital surveys are widely accepted as epidemiologic. Hospital reporting may contribute greatly to the enumeration of disease morbidity on state and national levels, as illustrated by various cancer registries<sup>17</sup> and studies on patients discharged from mental hospitals.<sup>18</sup> Hospital admissions may also be used as a gauge of unusual rates of acute conditions such as influenza.

Hospital data have also been used to describe demographic and geographic patterns of disease. One can relate the demographic data available in the hospital records of cases who reside in a defined geographic area to various census statistics of the general population

of this area.<sup>19b</sup> In this manner, estimates of the frequency of hospitalized cases of a disease may be obtained according to many factors such as age, race, sex, marital status, and religion. Socioeconomic factors can also be evaluated by analyzing the hospital pay status of cases and controls or by analyzing the census tract residences of the cases and the community population according to median monthly rental statistics provided by the U. S. census.

Studies of geographic patterns can perhaps be illustrated best by investigations conducted in the Veterans Administration hospitals throughout the nation and Puerto Rico. For instance, Acheson and Bachrach confirmed that multiple sclerosis in veterans became progressively more frequent from south to north in the United States.<sup>20</sup> Such studies obviously provide important clues to the etiology of a disease, especially in the case of rare conditions.

Hospital data can sometimes provide information bearing on the familial occurrence of disease, e.g., hypertensive toxemia of pregnancy.<sup>21</sup> My colleagues and I have used patient and parental name information from hospital records to determine familial occurrence of Hashimoto's disease among hospitalized patients.<sup>22</sup> One must be wary of the possible selection biases operating in the use of hospital patients as index cases for family studies.<sup>23</sup>

Comparative studies of the hospital charts and death certificates on patients dying in hospitals may reveal systematic errors of classification made on causes of death as stated on death certificates. For example, scleroderma may not be indexed as the underlying cause of death because it is included in the International Classification of Diseases under diseases of the skin and cellular tissue. The coder may not know that scleroderma or, preferably, progressive systemic sclerosis is a generalized disease which is often fatal and which

**Table 2—Epidemiology in Hospitals**

Some Organizations Studying or Employing This Method

1. World Health Organization  
Expert Committee on Health Statistics  
Subcommittee on Hospital Statistics<sup>19a-b</sup>
2. National Health Service<sup>24</sup>
3. The Oxford Record Linkage Study<sup>25</sup>
4. United States Department of Health,  
Education, and Welfare  
National Center for Health Statistics  
(General) Hospital Discharge Surveys<sup>26</sup>  
National Institute of Mental Health,  
Biometrics Branch  
(Mental) Hospital Studies Section<sup>27</sup>  
(Mental) Outpatient Studies Section<sup>28</sup>
5. Veterans Administration  
Research in Geographic Epidemiology  
Section<sup>20,29,30</sup>
6. Commission on Professional and Hospital Activities<sup>31</sup>
7. State-wide Tumor Registries<sup>17</sup>
8. Indiana State Board of Health  
Experimental Hospital Morbidity  
Study<sup>32</sup>

affects many organs in addition to the skin. Such a systematic error in death certificate coding was actually found in a Baltimore-wide hospital survey of mortality from scleroderma.

Although epidemiologists are not usually concerned with the administrative problems of a hospital, such as utilization of present facilities or evaluation of future needs, they can nevertheless contribute their analytic methods to solving such problems.

A number of international and national organizations are already exploring the use of hospital data in epidemiologic research (Table 2). In fact, the Expert Committee on Health Statistics of the World Health Organization recommends that

“. . . countries should take all possible steps to improve the quality of hospital admission-discharge records and recording procedures with a view to their use in statistical surveys

or systems to provide measures of hospital utilization and indicators of community and national morbidity patterns.”<sup>19c</sup>

Not all diseases and not all hospital systems will be advisable for community-wide hospital surveys. One must consider the appropriateness of the disease to be studied by this method as well as the hospital system in any particular community (Table 3).

Three recent epidemiologic studies using solely or primarily hospital-detected cases will serve to illustrate some of these points. Siegel and his asso-

**Table 3—Epidemiology in Hospitals**

Considerations for Evaluating the Appropriateness of Disease and Hospital Systems in Community-wide Hospital Epidemiology

A. Appropriateness of the Disease

1. The condition should be diagnosed or treated conventionally in a hospital.
2. The disease should be one that can be defined adequately, preferably by a uniform, objective criteria, and determined by standard techniques.
3. Although infrequency of the condition at any one institution is a positive indication, it is not a necessary consideration.
4. No evident selection for hospitalization, such as ethnic, socioeconomic, or associated disease, should be present.
5. More than one type of hospital control group should be available whenever possible.

B. Appropriateness of the Hospital System

1. It should be in a defined population with available census data.
2. It should serve the large majority of known cases originating in this population.
3. There should be no significant migration of selected population groups to hospitals outside of this area.
4. Specialized referral hospitals, whose cases may be derived in majority from other populations, should be analyzed appropriately.
5. Uniform access to all hospital facilities should be available to the investigator.

ciates have described the epidemiology of systemic lupus erythematosus (SLE) in New York City.<sup>33</sup> Monk, Mendeloff, and Lilienfeld are conducting an epidemiologic study of ulcerative colitis and regional enteritis in Baltimore.<sup>34</sup> Also in Baltimore, there has been a study of the epidemiology of Hashimoto's disease, a thyroid disorder of unknown etiology.<sup>35</sup> Each of these uncommon diseases is either conventionally treated or reliably diagnosed in hospitals. The investigators in each study initially set up criteria for the definition of a case; for example, three or more systemic manifestations plus confirmatory laboratory evidence were used to define a case of SLE. In the study of Hashimoto's disease, only histologically diagnosed cases were included in the survey. Regardless of how carefully one attempts to define a case, variability in diagnosis will always occur. Attempts to evaluate this variability should be done.<sup>36,37</sup> Attempts should also be made to identify selection for hospitalization according to various personal characteristics and associated diseases.

The hospital system in Baltimore seems to be adequate for the epidemiologic studies. Each of the two studies was conducted in defined areas for which the population characteristics were known. In Baltimore, for instance, all 16 private general hospitals and the four government-supported hospitals are located within the urban area; moreover, no significant migration of urban residents to other areas for medical care is likely to occur. Attempts should be made by the epidemiologist to gain access to all hospitals in a system on a uniform basis because selection factors for admission to certain hospitals, e.g., religion or socioeconomic variables, might otherwise bias the results.

The fact that hospitalized patients are a selected sample of all persons with a disease in a population may limit their

value in epidemiologic studies. Certain hospital selection factors (age, race, sex, and socioeconomic status of the patients) are usually of unknown magnitude; and their importance varies with the disease under study.

Illnesses like leukemia which require eventual hospitalization might not be seriously biased by these selection factors. On the other hand, conditions like asthma and arthritis are usually treated on an outpatient basis and statistics based on hospitalized cases would be of less epidemiologic value.

The more advanced cases of a disease tend to be admitted to hospitals, a practice which gives an exaggerated impression of the severity of the condition. Disease statistics based on hospitalized cases might thus be incomplete and biased with regard to demographic characteristics. For this reason, a repetition of hospital-based studies in several areas would allow for greater confidence in the results, if they concur. If an attribute to be studied in hospitalized cases (e.g., cigarette smoking) does not independently influence admission,

**Table 4—Epidemiology in Hospitals**

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Potential Limitations

1. Hospital detected cases are not inclusive and are selected according to:
    - (a) Personal characteristics, e.g., age, race, sex, socioeconomic status
    - (b) Severity of disease with a tendency to advanced cases
    - (c) Associated conditions
    - (d) Administrative admission policies.
  2. Difficulty of finding adequate control groups.
  3. Hospital records are not primarily designed for research, because of:
    - (a) Incomplete and unstandardized information
    - (b) Diagnostic variability among hospitals.
  4. The community population at risk cannot be precisely defined.
  5. Duplicate admissions raise problems in determining incidence and prevalence rates.
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however, then the hospitalized cases will show the same relationship with the attribute as exists in the population.<sup>38</sup>

When we seek to establish associations between diseases, spurious results can be derived from hospital data, as Berkson has shown.<sup>14</sup> If one is able to choose a control disease which has the same independent probability of causing the patient to be admitted to the hospital as the disease under study, then this type of hospital selection may be avoided. A comparison of the frequencies of the associated conditions in the case and control patients is then theoretically valid. For example, if one wished to study the diseases associated with Hashimoto's thyroiditis, usually a mildly symptomatic condition, the proper choice of a control would be another mildly symptomatic condition rather than an acute illness usually requiring hospitalization. Because one cannot determine accurately the true probability of admission to hospital for any one disease, the use of several separate conditions as independent control groups is advisable. We should beware, however, of including among the control diseases those which are etiologically related to the disease under study, because this will tend to diminish the chances of demonstrating a positive association when one actually exists.

The choice of a proper control group when doing hospital-based studies is difficult. Ideally, the controls should be picked so that the important variables affecting the frequency of the attribute under study are adequately matched with the cases. The age, race, sex, and hospital admission service of the patients are among the most important variables. Special referral policies or hospital admission practices can cause difficulties, because they might inherently bias the cases and the controls might not adequately adjust for this. Regardless of careful matching, it is advisable to test the adequacy of the con-

trols by studying the frequency in both groups of several attributes which a priori might be expected to be randomly distributed. With such precautions, the data can be collected with greater assurance that the subsequent statistical analysis will be meaningful.

Hospital records are not kept for research purposes primarily but rather for the care of ill individuals, as they should be. The statement is often made that such unstandardized and frequently incomplete data cannot be used for research. This is too strong a statement, in my opinion. One of the many rewards to be derived from epidemiology in hospitals will be a realization of how hospital record-keeping can be improved for the benefit of the individual patient as well as for research.

The inpatient summary sheet, or "face" sheet as it is sometimes called, is usually kept primarily for administrative purposes, in contrast to the body of the hospital record discussed above. Community-wide hospital surveys will usually depend chiefly on the face sheet information, which includes (1) the personal characteristics of the patient, (2) the hospital admission service and duration of stay, and (3) one or more discharge diagnoses. Because the hospital record room diagnostic index is based on information from this sheet, however, the detection of cases for both types of studies is influenced by the accuracy of diagnoses specified there. For some studies one may resort to other indexes sometimes kept in hospitals, such as the record room index of surgical operations or the surgical pathology diagnostic file.

In Baltimore, each of the 16 private hospitals has a diagnostic index dating back to at least 1954 and a record room librarian. In addition, since 1954 each hospital has had an independent index of operations. Furthermore, most of the pathology departments in these hospitals have a diagnostic index; and all of

them have copies of surgical pathology reports bound in volumes in chronologic order. Thus, in Baltimore the medium- and large-sized hospitals, which presumably do not differ greatly from hospitals in other cities, already provide reasonably adequate diagnostic indexes which can be used for detecting cases in epidemiologic studies.

In general, the completeness of hospital diagnostic indexes has improved markedly over the past 15 years, partly as a result of adaptations in the International List of Causes of Death since its sixth revision in 1948.<sup>39</sup> These improvements have allowed the list to be used for the first time for morbidity as well as mortality statistics. Furthermore, the increasing use of the International Statistical Classification of Diseases allows greater comparability of discharge diagnosis statistics among hospitals.

Because of possible diagnostic variability among hospitals, an increase in the number of institutions participating in a study may greatly improve the chances of obtaining a more representative result. The amount of such variability can usually be evaluated in multiple-hospital studies. In prospective studies, standard criteria for diagnosis can be agreed upon initially and certain laboratory or pathological examinations can even be referred to central laboratories. Exchange of specimens between collaborating institutions is important to determine interhospital bias in diagnosis. The repeatability of observations should be tested in order to estimate the magnitude of random error. Furthermore, whenever possible, tests should be done "blind" to reduce observer bias.

Although one can geographically define a hospital service area, it is not possible to determine precisely the population at risk in that area, for the reason that hospitals do not serve precisely defined populations. Most investigators

have accepted the U. S. census population statistics as a measure of any given population at risk.

Finally, because of the possibility of duplicate admissions, a distinction should be made between numbers of cases and numbers of discharges. Data on numbers of discharges can be reduced relatively simply to numbers of persons by matching on the names of the discharged patients and their parents.<sup>22</sup>

## Discussion

The principal records used by the epidemiologist at various times and for different diseases have been the death certificate, the form for physician notification of a case of communicable disease, the laboratory reports obtained during population surveys, and the interview schedule form. To these should be added various documents from the hospital record, such as the inpatient summary sheet and pathological report forms, and the various diagnostic indexes (surgical and pathological) often found in hospitals. The optimal study, of course, would combine the use of all resources to obtain health information on a population.

Before embarking on any epidemiologic studies involving hospitals, it is essential to have a question or an hypothesis about which reliable information is likely to be obtained. It is not a question of deciding whether hospital surveys are better than community surveys, or vice versa. Which method seems more appropriate in any particular circumstance is the relevant consideration. On the one hand, hospital-based studies are likely to be somewhat biased with respect to case selection; but they can provide a valuable source of highly technical, specific information about disease. On the other hand, a community survey will give a more representative sample of the population and will likely allow

for more standardized research technics; but the amount of information about disease is limited usually to interview responses or relatively simple tests. Several studies comparing interview responses with medical records have indicated that only a small proportion of chronic conditions diagnosed by physicians had been reported by the respondents.<sup>40-42</sup> In addition, one cannot expect to obtain entirely accurate information about a medical diagnosis from interview, even when the patient knows of the condition. Thus, in deciding whether to use the technics of hospital epidemiology, one must consider many factors: the aims of the research, the disease under study, the availability of hospital resources, and the research funds available.

An almost unlimited variety of studies using epidemiologic technics can be carried out in hospitals. In fact, the field is still in its infancy; and only time will reveal the eventual possibilities. That such a wide variety of investigations will be conducted exclusively by epidemiologists is unrealistic, since the scope of studies range from clinical research at one extreme to hospital statistics at the other.

One can theoretically partition this field among various specialists—the clinical or laboratory trained specialist, the epidemiologist, and the statistician. The former can participate most actively in epidemiologic studies within hospitals because his intimate knowledge of the disease under study offers him a special advantage. The epidemiologist will likely center his interest on descriptive demographic and geographic studies of disease. The statistician will probably work most closely with administrative persons in estimating disease morbidity and evaluating trends in hospital utilization.

Although these divisions are theoretically feasible, no clear-cut demarcations between the various types of studies

could ever be drawn. In this era of technical specialization, epidemiology in hospitals will best be performed as cooperative ventures including at least the three above-mentioned specialists. Furthermore, a cooperative study might serve multiple purposes. For instance, it may serve as an indicator of morbidity; it may uncover interesting patterns of disease; and it may suggest better methods of diagnosis and treatment.

Under these circumstances, what we accomplish as epidemiologists will depend greatly on the initiative and enthusiasm which we bring to the task. Even if the epidemiologist is not able to carry out completely a particular study, he should at least contribute at the beginning to the development of the design and initial conceptualization of the study. The epidemiologist's participation helps guard against the temptation to process masses of hospital data indiscriminantly, a problem in this era of advanced electronic processing instruments. There is no substitute for searching out specific questions which can be answered by hospital data and for personal investigation of possible idiosyncrasies in the data which might result in unrecognized inaccuracies.

Serious consideration will have to be paid to the equitable utilization of hospital records for the purposes of epidemiologic research. At present, the epidemiologic studies in hospitals have been few and mainly of uncommon conditions; and they have not imposed a serious strain on the cooperating hospitals. In the future, however, as studies grow in number and size, acceptable arrangements will have to be made with hospital officials to cover the cost of such research activities. For instance, problems in the record room of space, time, and personnel must be considered.

Inducements should be offered to hospitals to increase and maintain the efficiency of their diagnostic recording practices, because this will eventually

lead to a marked saving in time and effort in searching for the necessary data.

Hospital officials should be assured that detailed case reports from their own institutions will not be published and that primarily statistical analyses will be made. Of course, patients or their physicians would not be contacted without obtaining the required permission. Assurances must be given that the identifying information contained in records under study will be treated ethically and in the strictest confidence.

The costliest element in hospital epidemiology is probably the investigator's time. To insure the maximum cooperation and the greatest possible standardization he should personally visit the individual institutions and the responsible persons there who could provide both the permission and information required. Moreover, the epidemiologist can expect only to be able to work with the hospitals; he cannot expect the participating institutions to do more than provide the records necessary for his study. The epidemiologist will not usually find himself working alone, however. It has been gratifying to experience the enthusiasm which clinicians develop for epidemiology once they realize its application to their own specialty.

### Summary

Hospitals provide many opportunities for productive research using epidemiologic technics. The extent to which such goals can be achieved depends upon our ability to identify and overcome the limitations of this method. This paper has outlined both the potentials and the shortcomings of epidemiology in hospitals; and it is intended to stimulate further thinking in this direction rather than to provide definitive solutions.

Dr. John Gordon has said that the whole methodology we use in approaching disease is within one of three direc-

tions—the clinical study, the laboratory investigation, and the epidemiologic analysis—and that we need more application of the latter. The hospital can provide the setting in which such cooperative efforts can be realized and in which epidemiology can further contribute its insight and direction.

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