Lecture II: ROLE OF EPIDEMIOLOGY IN SCIENTIFICALLY BASED PRACTICE: EPIDEMIOLOGIC SURVEILLANCE AND COMMUNITY DIAGNOSIS

In the last lecture, we were talking about some f the reasons why an improvement in the scientific quality f public health practice is needed . This lecture will be used to illustrate some f the contributions that epidemiology can make toward improving this quality of practice.

As indicated last time, the first prerequisite for any intelligent public health program is knowledge f the extent and distribution of the problem under consideration. Traditionally this has meant a study f the extent, and the distribution of, various diseases'in any given community. This study of the distribution f, and extent of, diseases in communities has been, and will continUeto be, one of the essential functions of epidemiology. In fact, one of the more widespread definitions f epidemiology is just that. McMahon, in his book Epidemiologic Methods, defines epidemiology as the study of the distribution and the determinants of diseases in populations. Morris, in The Uses of Epidemiology, has a slightly different definition; "Epidemiology is the study of health and disease in populations in relation to their environment and ways f living." While there are numerous other defintions of epidemiology which are variations on this same theme, it does not appear very useful to consider them all as they do not clarify some of the more important questions about epidemiology and its potential contributions any more than the ones cited above. None f the definitions for example make explicit what is meant by determinants f disease nor which f these determinants are amenable to epidemiological

studies. Neither do they define any more clearly what Is included In the term environment. This can be interpreted to mean the physical environment (which is the usual concept) or more broadly the human environment as well. These are issues which will be discussed later in this course. One thing which all defillitionshave in common however is their emphasis on the unique features of epidemiological studies, a feature that distinguishes such approaches from other means f health investigation. This is that the unit f study in epidemiology is a population, or group, or an aggregate of people, rather than an individual. This means that the kind of question that an epidemiological study can answer is why certain categories f people, with certain types of characteristics, have more or less disease than other types f people, rather than why any one individual gets sick at a particular point in time. It is thus able to describe how the health status of different communities varies and hopefully offer some explanation for such differences.

In order to develop information concerning the distribution and extent of diseases in a community, that is to provide knowledge f the extent and scope of the health problems, three things have to be understood.

First, the investigator must know something about the indicators of the health problem - that is how the condition that he is studying will be measured. In other words, there must be a clear defintion of who shall be counted as a case and who shall not be counted as a case. If, for example, he wishes to determine how much mental illness there is in a county or a state, then he must define operationally what he is going to call mental illness. Is this going to be just those people admitted to a psychiatric

hospital or is this going to he those who go to a private psychiatrist? Is It going to he those people admitted to a psychiatric hospital, those who go to a psychiatrist, and also those people who are not admitted to a hospital but who are still in the community and who have certain characteristics which will allow them to be labeled as a case or not? The way in which the cases are labeled becomes a crucial point and one must know for any given study the advantages and disadvantages of various ways of indicating or labelling cases and what sort of inferences are, and are not, possible, depending upon how the cases are labelled. The same thing would occur if one were studying the prevalence of delinquency. Would he label delinquents as only those apt to come to the attention f the police? This has some advantages, but it also has some built-in biases.

If one wishes to study the prevalence of accidents, then he must define what he is going to call an accident. Does he include as accidents any sort of injury, e.g., any time the skin is broken, or does he include only major accidents? If so, what would be major? These are the sorts of questions that any investigator must face. Thus, the question f the indicators used to measure the distribution f the condition becomes extremely important and this is where each person must bring his professional knowledge f the subject together with his knowledge f epidemiology in order to make a decision. If one is a specialist in accident-prevention, for example, he must then bring together his knowledge of the advantages and limitations of the different ways f classifying accidents in order to do any intelligent study.

The second point is that the investigator needs to know some f the methods for describing the frequency of occurrence of the characteristics and/or the condition in the population or group being studied. In describing the frequency of occurrence in a population or group there are a number f terms which are used in both epidemiology and biostatistics. These are such terms as period and point prevalence, incidence, mortality rates, case fatality rates, and a number of others. These are the various measurements which we use and each one can be used precisely to describe how many or how few of the cases being studied are occurring in a population.

Thirdly, one must know the peculiarity, advantages, and disadvantages of the sources from which the data come. Each particular source of data has its own set of built-in errors and built-in biases which will determine what and how much one can infer and interpret from that particular data. The investigator must know for each condition that he is studying the particular attributes f the source of data.

For example, if he wanted to know how much serious disease was occurring in a particular population he might go to the vital statistics data f the United States and look at the major causes of death. In this data he would find the major causes f death to be heart disease, cancer and stroke. If instead of, or in addition to, looking at the causes of death one looks at the conditions which cause people to get into hospitals he will find that the chief cause is injury, followed by such things as hernia, and heart disease. These might vary somewhat depending upon the particular hospital or the particular region being studied, but it would not be the same list that one would find as the cause of death. If, in addition to looking at causes

for admissions to hospitals, one looks at the things that take people to doctors in general practice outside of hospitals, th^ conditions which are responsible for hospital admissions are not the same as the conditions that bring people to doctors. The conditions which send people to the doctor's office are upper respiratory infection, injury, and "rheumatism" or muscular aches.

Finally, if one is doing a population survey and knocks on doors and asks people what their complaints are, the most common complaints given would be headaches, nervousness, and gastric troubles. For these reasons, the simple-sounding questions of how much disease there is and what the important diseases are in a particular population might be answered in four or five different ways depending upon the source of the data. It is obviously important to know what the source of data is in order to know what inferences can and cannot be drawn from it. It is also important to know that one is going to get a different distribution f labels and diagnosis f conditions, depending upon the source of the data. If, for example, you take a county, or a sample f that county, f 1,000 adults and ask them in the course of the past month how many f them had complaints of any sort of illness of any sort f symptom, about 750 would have symptoms during that month. Of those 750 people, 250 would have consulted a doctor. Of the 250 that consulted a doctor, about 9 would be admitted to hospitals and f these, one would be admitted to a university teaching hospital. It is obvious then, that if one looks only at university teaching hospitals he is getting a very selected sample f the

total number of people who had symptoms during that month. The sources f data not only dictate the types of complaints which are likely to be less common, but the types of people upon which the data is based. Chapter 6 f Epidemiological Methods describes some of the sources f health data and their limitations.

Although such information on the distribution of diseases and the extent f these diseases in populations is still essential for the careful development f programs, and forms the essential core of information that should be constantly available to all operating health agencies, it is now recognized that such information alone is insufficient for epidemiologic needs and the needs of developing relevant programs. It is insufficient in two respects. First, the concept of disease needs broadening to include a wider range f human problems. It should include such things as how many premature births are occurring, whether there are too many births occurring, (the population explosion), the occurrence of drug addiction, the problems f industrial growth in rural areas, to name but a few. In other words, the human problems which are meaningful, and for which we need to find answers, are not restricted to the occurrence of narrowly defined medical conditions but include a whole host of social problems that may be associated with medical problems. These social problems are sometimes indistinguishable from the medical problems and need to be included in our epidemiologic surveillance system.

Secondly, not only should the extent and distribution of these problems be known by any adequate epidemiologic surveillance system but the

community diagnosis should include information on what is being done about the problems, how it is being done, and what is the readiness of the community for new or additional services. One needs to know not only the extent f the problems but also what attempts are being made to remedy them; how well the attempts are succeeding; and how ready the community is for innovations or changes. This aspect of community diagnosis or surveillance, i.e., the application f epidemiology to defining the problems is difficult to come by. It cannot be obtained in a short period of time and requires a deliberate and conscious effort to develop the machinery to obtain, to interpret, and to act upon such information. In other words, there is no point in collecting such information purely for the sake f collecting data. This is an area which is almost totally unexplored. The understanding f what is being done, how well it is being done, and how ready the community is to act upon it, is not currently available in any textbook, nor is it linked together in any systematic fashion. A summary entitled "Epidemiological Surveillance and Community Diagnosis," is available from this Department and should be of use with this lecture.

What kinds of data can and should be gathered, what should be the indicators or the measurement tools used in a particular community is a complex matter. Few people have come prepared to deal with these questions. But each one must address himself to the needs for these sorts f questions and the way they can be answered from his own prfessional or disciplinary viewpoint. For any community, in addition to a knowledge f how much disease,

ill health, symptoms, or whatever e need to know the pattern f utilization of existing health services, We need to know who uses what health services and for what purposes. How many people, for example, take their complaints to the druggist, or to the faith healer, or to the grandmother? How many people take them to doctors, to the nurse, to the hospital? What determines where people take their complaints? Who are the decision-makers in any community? These are the problems that should be the area of concern to the people who are specializing in health education. How do you determine who the decision-makers are in any community? What is the network of relationships that occur in a community that lead people to selecting a particular source f health services? How does a newcomer to a city or to a community find cut about the available health services? There are no welcome wagons and no advertising. Where does he find this out? Is it by word of mouth and if so from whom? If there is a social service or public health nursing service available, are they being used? What is the relationship between the hospitals and the community services? Are patients being discharged from hospitals to communities without any adequate preparation for them within the communities? The physician would never dream of admitting a patient to a hospital ward if there were no staff available for that ward; if the nurses were not available the hospital would close the ward. Yet we think nothing of admitting patients back to the community without any services at all even though they need continuing services.

What are the existing methods for financing these health services and

how adequate or inadequate are they? How should we measure utilization? Over what period of time? How do we get this data? If we ask people about their patterns f utilization over the past year they will have forgotten a great deal of what they have done and perhaps give inappropriate information. If we ask for too short a period of time, it is not possible to get enough f the spread. All f these questions are important and these are the kinds of questions that individuals with interests in the delivery of health services are going to have to wrestle with in the years to come.

(2) Secondly, the needs for additional services or facilities must be determined; and what these needs are going to be is dependent upon whom you ask. These needs as seen by the professional practitioners, by the potential utilizers, by the population, and as seen by prfessional consultants may, and probably will, differ constantly. Do you need more hospitals or different hospitals? Do you need to set up community services, or more extensive community services?

Thirdly, what is the impact of ill health on the community? How much disability is being created by the diseases that have been identified as being important? How much does this interfere with work, with school, with earning money, and with productivity. Is it possible to measure this in terms of cost in terms f human suffering? A study done in Boston a few years ago illustrates the social problems and personal problems created by or associated with ill health. A group of people from the Massachusetts General Hospital interviewed some hundred families, all of whom had one child

with a chronic handicapping condition and they found to their chagrin that something like 85 percent f the major problems these families had faced as a result f having a handicapped child had never become known to the health services. The health services, though they were good, were concentrating on a particular handicapped condition; the associated educational problem, financial problem, marital problem, and a whole host f problems that were created by the presence f a handicapped child were not considered germane to the health service.

As another example, some people in Florida at the Alcoholic Rehabilitation Center decided that they would like to change their approach from trying to rehabilitate the alcoholic himself over a period of several months, to trying to provide a family therapy. In order to do this they brought in all adult family members of the alcoholic patient to see if they could work with the family in a more effective way. In the initial phase f the project they had the public health nurses interview a sample f such families to find out if they would be willing to participate in such a program. The nurses found out to their astonishment that the presence of an alcoholic member in those families was only one of a multitude f problems and ften the most minor problem that the family was facing. The fact that the husband was alcoholic was f some concern, but f only minor concern when compared to the other sorts of problems that that family was facing, all of which had been systematically overlooked by the health services concerned with the alcoholism or any other types f specific

categorical disorders. So the questions should be concerned with ramifications of ill health in families in communities; and the additional problems it creates.

Individuals concerned with the delivery of health services must become less circumscribed in their definition f a health problem. For example, a baby comes to the pediatric clinic with severe diarrhea and dehydration. How do the medical people view and deal with this kind f problem? Is it simply viewed as a problem f infection of the gut and some disturbance of electrolyte balance, and dealt with by providing antibiotics or some other drug and by restoring the balance between the electrolytes in the baby. Is the fact that this baby comes from illegitimate parents who live in substandard housing, or that the parents are alcoholic, defined as part of the problem? It is seldom included as part f the concern of the people treating the diarrhea. Whose responsibility should it be? Who should know about it? How does this information become visible so that something can be done about it? So this, the social and personal problems created by or associated with ill health is a very large area and one that we are only beginning to touch. This is becoming even more dramatic today with the increasing militancy in the inner-city and ghetto populations, who are protesting vigorously about the quality and quantity of the medical care they receive. What these people are protesting about is not so much the fact that they cannot get antibiotics when they need them, or the fact that they cannot get high quality surgeons when they need operative care, but rather they are complaining about the fact that the host of associated problems which are in essence an integral part f their medical problems receive little or no attention in the system of health care

currently available to the poverty-stricken population f that area. Individuals who have faced the problems f trying to provide health services to such populations agree that the central problem is the failure f the health services to provide their care based on an understanding f these associated problems.

The fourth area of concern should be with the content and the quality f exi ract* The first item in this area seems to be a terribly important question which we need to address ourselves to; that is the degree and adequacy f communication between professionals and patients. In the few studies that have been done in this area a nurse has sat in the doctor's ffice with the patient and listened to what the doctor says about the disease to the patient; what advice he gave the patient. When they left the office, immediately after the door was closed, the nurse asked the patient, "What did the doctor say?" They found that in something like 75 or 80 percent of the times the patient received a distorted view f what they thought the doctor said. The communication had not existed, no matter how hard they had tried. The point is, that if there is anything that is important in the relationship between a health professional and the population served, it is this quality of their communication. It appears that nurses are far better at communicating than are physicians; health educators presumably could be even better. All individuals concerned with the delivery f health serviecs must be concerned about how adequately their messages are getting across, whether these are the messages between a practitioner and an individual patient or whether these are the messages that are being dissiminated to total populations or to groups f people.

Another Important area of concern Is the degree of continuity of care for the Individual Continuity of care has become an important issue in the delivery f health care and seems to imply that services should he continuous, comprehensive, and so on. Yet few people have attempted to define what they mean by continuity f care. This kind f care is very difficult to provide in a mobile society such as ours with a reasonably free choice f health services. Nevertheless we must know to what extent for any given individual, there is a knowledge on the part of the people providing the care at any one point in time what has gone before and what is going to come afterward. For those people who have a chronic long-term illness the severity f the illness varies over time; at times it is acute, at other times it improves, and they need different levels of care at these various times. Sometimes the patient must be admitted to a hospital; at other times to a rehabilitation center; sometimes they need physical therapy; sometimes they need the servies of a nurse at the home. These are the questions that the people in health services research need to address themselves to.

Once more we are faced with the need for indicators, for means to measure continuity, to be able to interpret the results. Not only do we think about continuity of health services as connected with individuals, but also the continuity of health services for the family or the group. How many families are there in which the care f one individual is in the hands of one agency and the care f another individual in the hands of another agency? Particularly in impoverished and underprivileged

families one can find seven to nine different agencies providing services for any family, each agency in ignorance f the other. The family is visited by a barrage f people from the health and welfare . departments, from family agencies, from the courts, from a number of charitable organizations, with the result that the right and left hand know not what they do. There have been few attempts made to organize this delivery f health services, or even to make a set f diagnostic statements about what needs to be changed to deliver care to this type of family, or who should have this responsiblity. By the same token, the degree to which preventative, curative and rehabilitive services are integrated, follows a similar pattern.

This is recognized as a difficult area but one which must be explored in greater detail. We are told every day that one f the problems with health services today is a shortage f personnel. There are not enough doctors, not enough nurses, and we at least need to double or treble the number f graduates being trained. Let us take the question of doctor shortage for example. If one looks at four countries across the world, Israel has a doctor-patient relationship of something on the order f one doctor for every four or six hundred population, the United States only averages one doctor to every 800 to 1,000 population, Britain averages one doctor to every 2,500 to 3,000, Scandinavia averages one doctor to every 4,000 or thereabouts population. There is little difference in how busy the doctors are. There is little difference in how long people have to wait to get to a doctor. There is, in fact, in some of the countries with the fewest doctors, a better health record. Scandinavia has lower death

rates than the United States, yet has fewer doctors. The number f doctors appears to be less important than how efficiently their time is being used. The same is true for nurses, for social workers, for any other category of health professionals.

The time is now right to start exploring something about the degree to which existing training is being utilized efficiently in practice. Are the roles that individuals are called upon in their prfessional health work consistent with their training? How much f the time f the nurse, for example, is spent in administrative work that could be better done by a clerk? How much f the time of a doctor is spent in gathering data that could be better gathered by a social worker? These are the sorts f questions to which answers must be found.

The final_area ofinterest_ is aoncPrned_with the service load, the number of patients, the type of_condition, the types of actions taken. For these there are more or less standard types f data that are being gathered in these areas. We do know about how many patients are seen by health departments. Information is available about the activities f public health nurses, doctors and so on, but this is only a statement f activity and cannot be usefully interpreted outside f the context f what it is collected for. The information presented in this lecture is to provide you with some new ideas of what sorts of new data need to be gathered in epidemiological surveillance and community phenomena, to devise indicators for changing health states as you devise methods for acquiring these data. This is going to mean in the future that individuals in health services research must have a far more intimate liaison with the providers of health services, with the physicians,

with the hospitals and with health departments than they have had in the past, so that their experience can become more common knowledge and can be utilized. The irony is that the technology is available today in the form of computers and data processing; what has not yet been developed is the human mechanism to make this data available and interpret it as needed.

In addition to understanding something of the nature f the distribution of dtsease in a community and the patterns of what is being done about them, we must also be looking into the future. We should be gathering data that will provide us with some predictive powers. We have seen how rapidly and in what direction health problems are going to be chancing to in the future, we must develop epidemiologic surveillance systems to provide early warning signals so-that it will be possible in the future to change the character and the content of our health services to make them appropriate for the developing problems.

There is the need to do this in three or four different areas. First, all the efforts to determine the harmful effects of the introduction f new elements into the environment and into our ways of living should be continued. Many such efforts are being currently undertaken. Much work is being done to monitor the effects of air pollution; efforts are being made to monitor the effects f radiation; new work is being done to monitor the effects f the many new chemicals in the form of pesticides and in the form of food additives and things of that nature. There is machinery set up; they are still inefficient but they are being set up and we need to expand these efforts.

While there is this great need to be concerned with the Influence of these new technological changes, there is at the same time an equal need to he concerned with the impact f social changes. What is the vast and rapid rural to urban migration, for example, doing to the health f the migrants? What effect does it have on the people with whom they come into contact. We must add to our knowledge new information about the possible harmful effects f new changes occurring in our ways f living and in our environment. To do this we must not only have the machinery to monitor these effects, but we must do more research in the type f outcomes, the types of consequences which we might anticipate, Many times these consequences will not be clearly recognized disease states; they will be more subtle. They may express themselves as changes in productivity, as changes in biological and physiological elements, or as changes in the forms of behavior in the population. They might be reflected first in some simple way, such as a change f school absenteeism or something of that nature. It is impossible always to know beforehand all the p Bible harmful effects f new factors in the environment. Often we do not have the opportunity to know that new factors have been introduced into the environment until it has already occurred. We must set up some indicators of the changing nature of health, disease, and productivity in our population. We must have on a continuing basis an epidemiologic surveillance or information system to measure how people are responding to these new factors in terms f their health status.

A system such as this hasibeen established in a limited fashion for some of the major infectious diseases. The Communicable Disease Center in

Atlanta, for example, has an influenza surveillance and they measure over the whole year the fluctuations in death rates from infectious diseases such as influenza. As these begin to rise they realize that the country is starting a new influenza epidemic. They also have a continuous surveillance on cases of infectious hepatitis and poliomyelitis as well. We need the same for such disorders as coronary heart disease, lung cancer, stroke. This system should contain the mechanism by which we can find out if these are increasing, decreasing and whether new syndromes or new disorders or new manifestations of the disease are appearing in large numbers. We need something set up so we don't have another thalidomide tragedy before it is too.late to be able to anything about it. These alarm signals must be developed. They are going to take some f our best brains and some of our most concerted efforts to do it. And here lies one of the major challenges to those people in health services research.