Research Epidemiology as a Growth Industry at the National Institute on Aging

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THE KENT PAEDIATRIC SOCIETY published in 1954 a monograph entitled "A Study in the Epidemiology of Health" (*1*). The study was an ingenious attempt to evaluate health by arbitrarily scoring school children in England on a variety of parameters under the general headings of physical status, intelligence, and personality. The conclusions follow:

(1) The assessment of Health is a task of considerable difficulty calling for a combination of traditional clinical methods with somatometric and psychometric techniques some of which are still in the experimental stages.

(2) The study of Health is a supremely worthwhile objective but its claims to be regarded as a scientific discipline have yet to be fully recognised.

(3) Although not yet proved, it is possible, or even probable, that Health, no less than disease, may have its specific as well as its predisposing causes and that the true promotion of Health may depend, in the long run, on our acquiring a fuller knowledge concerning them.

(4) Systematic knowledge of the incidence and causation of Health would give added meaning and direction to medical organisation and social progress.

Recently, the National Institute on Aging (NIA) established an Epidemiology, Demography, and Biometry Program (EDBP). Our main interest as a functioning unit within the National Institutes of Health is to learn as much as possible about what makes successful aging. We will not attempt too many parallels or associations with the pediatric society's fine work on English youth. We will, instead, emphasize our approach in conducting research encompassing the beguiling and comprehensive mission of NIA that spans the biomedical, behavioral, and social sciences (*2*).

In pursuit of factual and usable information related to successful aging we have defined our program along two major subject lines. One involves developing a research data base and new methodologies which we call Population Dynamics and Analysis. Relying largely but not exclusively on secondary analysis of data, we are exploring who survives and the impact on society of those who survive, and we are expanding the applications of demography and economics to the study of health. In the second area, called Population and Clinical Research and Analysis, medical and social problems are pursued more directly, and we are collecting our own data for primary analysis but with an additional component for secondary analysis. These two approaches are not mutually exclusive and there is considerable and welcome overlap that permits us a broad range of disciplines and of methodological options for the testing of scientific hypotheses. The two areas, however, provide us with a basic organizational matrix.

Although we use a range of scientific approaches, epidemiology forms the unifying conceptual framework for the Epidemiology, Demography, and Biometry Program. Further, we are trying to interweave in our research a series of germinal concepts that permeate the wide array of our endeavors. These concepts include questions concerning the effect of economic status on health; the relationship between family structure, social and physical environment, and health; and the survivorship of specific race, sex, and geographically defined

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birth cohorts who achieve 65 or more years of age in terms of differential mortality occurring before age 65. Since our program is new, we cannot offer a neat, compartmentalized description and projection of our activities. We believe better understanding of our efforts and intentions will come through a presentation of current programs.

Population and Clinical Research and Analysis

Longitudinal studies. It is a great temptation in studying the elderly to rely heavily on the longitudinal approach. In the Baltimore Longitudinal Study of Aging, the Institute's Gerontology Research Center is following approximately 1,000 persons of various ages and, for the present, it is doubtful that we will start new longitudinal studies of this size. We have some practical and theoretical reservations concerning new longitudinal studies. Among them are problems relating to the difficulty in maintaining the commitment of investigators with the reality of uncertain long-term funding, the problems of sustaining the interest and participation of the population and, finally, the fact that specific health outcomes are rare and the numbers in longitudinal studies are frequently insufficient to reach statistical significance.

Perhaps a more original but, we believe defensible, reservation is that Medicare is in place and broad health insurance coverage for all ages is expanding. With these developments, we foresee a radical change in the notions of privacy. It will become too expensive, both in terms of lives and costs, not to have the complete medical history of a patient recoverable instantly from computer storage and available when he or she is seen by a physician. We point out that major shifts in attitudes toward privacy have occurred in the past. One hundred years ago it would have been unthinkable for the citizens of each town and city to agree to having their names and addresses published in a book and thus made public. Once people wanted telephones, however, such books became part of the culture. Therefore, we advocate intelligent planning toward that eventuality—when a relatively simple computer exercise can construct accurate histories of large numbers of persons with given specific diseases or patterns of illness—making the launching of new longitudinal studies of questionable value at this time.

Currently, however, we are taking advantage of several longitudinal studies to work on defined subissues relating to aging. The National Heart, Lung, and Blood Institute (NHLBI) is following populations in Framingham, Mass., Honolulu, and Puerto Rico, and the National Cancer Institute (NCI) is also using the Honolulu study population. Since 75 percent of the deaths in these populations will be from cancer or cardiovascular diseases, we are avoiding specific illnesses in our approaches. At present, the Program's staff is collaborating on a study of the quantification of disabilities in the Framingham population that we will subsequently relate to previous health data.

We intend to develop studies of the older cohorts in these longitudinal populations concerning such topics as the effect of lean body weight and body composition on longevity, the role of social and economic factors on health outcomes, and studies within the cohort comparing persons who do poorly or well following a specific illness, a loss of a loved one, retirement, or change in residence.

Reference populations. Perhaps influenced by the Kent pediatricians' survey of "A Study in the Epidemiology of Health," a major effort will be to develop reference populations of the elderly to observe in integrated studies of medical, socioeconomic, and behavioral aspects of health. Our approach is to define and describe a population of elderly persons broadly and extensively. Then we would conduct a series of hypothesis-testing, comparative studies to determine who does well under different social, psychological, economic, and physical circumstances. Family, environment, culture, religion, nutrition, mental status, availability and acceptance of the health provider, and many other variables are being considered. We will also use this population to study the natural history of certain minor medical complaints that are poorly understood by the medical profession. Although these complaints account for a great deal of human suffering, a physician is consulted only rarely and under unusual circumstances. These "soft" signs and symptoms include constipation, dermatitis, sleep disorders, and various forms of chronic pain and discomfort.

Nutrition. Most of our studies in general populations will involve nutrition. The Program's major effort to date has been to develop an interagency agreement with the National Center for Health Statistics to conduct a followup study of the National Health and Nutrition Examination Survey (NHANES) (*3*). Our group is the lead agency and the National Cancer Institute and the National Heart, Lung, and Blood Institute are collaborating in this effort. The National Institute of Alcohol Abuse and Alcoholism, the National Institute for Occupational Safety and Health, and the National Institute of Arthritis, Metabolism, and Digestive Diseases may also participate.

The first round of NHANES was conducted from 1970 to 1974. It was probably the largest in-depth survey

of health and nutrition ever conducted. Participants answered an extensive questionnaire concerning health and nutrition and received a detailed examination that included laboratory studies of blood levels of vitamins and minerals as well as a full battery of routine medical and laboratory procedures. This landmark followup of a national survey will indicate the types and patterns of disease associated with the findings of the initial survey. We believe that a followup examination is essential to further the state of knowledge concerning nutrition.

We suggest that it will be extremely difficult to relate nutrition with specific health outcomes in the elderly. Undoubtedly poor nutrition has harmful effects, but the traditional ways of determining these effects are inadequate and outdated. We do not see scurvy or pellegra or beriberi. As specific types of pollution of the environment increase and the population eats, primarily, prepackaged food and an excess of junk foods, life expectancy is increasing rapidly at all ages and particularly among the elderly. Through this followup examination there may emerge new patterns of diseases related to all these influences that are not obvious from past training, knowledge, or expectations.

Hypertension. It is now possible to lower blood pressure. It is not clear, however, whether it is necessary, beneficial, or harmful to do so if the hypertension is purely systolic with no evidence of a pathological condition. This can only be determined by a clinical trial of individuals selected at random and placed on different treatment regimens or placebos. Such studies are enormously costly and lengthy, but they are necessary. In January 1979, with NHLBI as the lead agency, a conference on Hypertension in the Elderly was conducted and current knowledge was reviewed. Although the task was recognized as formidable, the overwhelming consensus was that a trial was feasible, of considerable importance, and should be conducted.

Estrogen use and postmenopausal women. A constellation of facts has emerged that is causing considerable confusion and discomfort among physicians and postmenopausal women. There is no question that menopausal and postmenopausal women experience unpleasant symptoms such as hot flashes and vaginitis that are readily alleviated by the use of estrogens. Estrogens, however, increase the risk of developing endometrial carcinoma. Nevertheless, evidence indicates that estrogens are of use in preventing or arresting the development of bone loss and possibly osteoporosis. There are approximately 200,000 hip fractures in the United States per year. The great majority of them occur in older women and are associated with osteoporosis, suggesting that estrogens may be of great potential benefit in the prevention of hip fractures.

The EDBP staff conducted a meeting of experts to review current thinking and important issues related to this paradox (*4*). We have also summarized data indicating that use of estrogens among postmenopausal women has declined about 50 percent since the association of these drugs with endometrial carcinoma (*5*). The possible relationship to cancer is confounded by the fact that the incidence of endometrial carcinoma is increasing while the mortality rate is steadily declining. At present, the problems of estrogen use and postmenopausal women are beyond immediate and completely scientifically based solutions. Therefore, we conducted a technical consensus conference in September 1979 that brought together experts as well as a wide range of interested persons—from drug manufacturers to women's groups and the lay press. We reached some understandings as to how the physician and potential patient can evaluate most rationally the risk-benefit ratios of estrogens to individual women and to populations (6). There is no question now that many women suffer distressing symptoms attendant to menopause because they fear medication that may cause endometrial carcinoma.

Senile dementia. As the absolute number of people 65 and older increases and those over 75 years increase strikingly, we are all exposed more frequently to the consequences on individuals and families created by someone with senile dementia. We doubt that senile dementia is a part of normal aging since it occurs in only a small percentage of the elderly. Instead, we believe that underneath a miasma of terminology and syndrome there exists a disease or several diseases with specific etiologies, natural histories, clinical spectra, and pathogeneses. Although senile dementia is estimated to affect from 4 to 25 percent of people over age 65, no epidemiologic pattern has been clearly demonstrated.

It is not known if women are affected more than men or if those in different regions or with different medical histories or occupations and exposures are at higher risk of senile dementia. We are working with laboratory and clinical groups at the National Institute of Mental Health (NIMH), at the National Institute of Neurological and Communicative Disorders and Stroke, and with the Baltimore Gerontology Research Center to determine if laboratory or clinical data can be developed which would be of use in field studies. We are also engaged, through an interagency agreement with the lead agency, NIMH, in conducting a population-based survey in a specific area. In New

Haven, Conn., we are oversampling the population age 65 and older in a community wide survey of mental illness.

Simultaneously, we are developing protocols to conduct studies of elderly persons detected through population surveys to be at high risk of senile dementia and matched with controls with no obvious mental illness. Our approach is to develop in-depth studies from an open population rather than from patients who were detected through medical sources. It is possible that the patients with senile dementia who are brought to the attention of medical personnel are a selected subpopulation of burdensome or bothersome persons, and this factor may be hindering us from developing insights into the epidemiologic patterns of the disease.

Epidemiology of the last days of life. A considerable body of literature now exists in pediatrics as well as in the psychological field and the lay press about dying. Yet specific data on basic events associated with dying are lacking—such as who dies peacefully in his sleep, who dies in great pain, who dies in the presence of his family, who dies after a long illness with full awareness of his impending demise, and who dies suddenly with no warning. Further, the proportion of the dying who need and who actually receive pain medication is unknown. These are but a few of the questions that can be answered through careful epidemiologic and demographic analyses. There is great need for factual information concerning the events surrounding death and the real risks of certain types of painful and terrifying deaths. Knowledge alone can comfort and direct physicians, patients, and society toward the optimal approaches to dying.

As with our studies of senile dementia, we believe that such an investigation of dying must be population- and home-based. It is easy enough to find out how institutionalized people die, but a major issue is who becomes institutionalized and who dies at home and why. We have been developing protocols and attempting to graft an investigation of these questions onto other large surveys to gain access to a population that will have some 1,000 deaths during 1 year. There is some urgency in our collecting these data since the hospice movement is gaining great prominence, and it eventually may become another burden on the health dollars spent by the Government. The entire movement is emerging with little information as to the actual or potential use of hospices and the extent of need for their humanitarian and inspirational services.

Miscellaneous studies. We will confine this section to mentioning a few investigations in which both primary and secondary data sources are being used in areas of specific interest. These studies include the epidemiology of osteoporosis and its relation to hip fracture. We would also like to know the rate of hysterectomies and the trends over time for this procedure. More careful studies concerning the morbidity and mortality of accidents among the aged population are being developed. We are testing several nutrition questionnaires in general use in elderly populations in different socioeconomic, geographic, and ethnic situations. We are also trying to determine if the great reduction in mortality from stroke has been accompanied by a parallel diminution in frequency of paralysis of recent and sudden origin, or if the decline in mortality simply means that we are saving more lives while increasing the number of severely incapacitated people.

Population Dynamics and Research Analysis

Research data bases and methodologies. We are attempting simultaneously to develop an overview and to become a reference point of statistical data for research on aging. Demography and economics are central disciplines in this enterprise. Initially, we will concentrate on the enormous Federal data sets that have not been exploited systematically by researchers on aging. Among these data sets:

1. Numerous surveys and studies of the National Center for Health Statistics
2. Longitudinal Retirement History Survey of the Social Security Administration
3. Bureau of Labor Statistics Longitudinal Survey
4. Bureau of Labor Statistics Consumer Expenditure Survey—Diary and Interview Sections
5. Current Population Survey of the Census Bureau
6. Annual Survey of Housing of the Department of Housing and Urban Development
7. Food Consumption Survey of the Department of Agriculture
8. Medical Care Utilization and Expenditure Survey (Medicare-Medicaid Survey jointly conducted by the Health Care Financing Administration and the National Center for Health Statistics)

This list, of course, is not exhaustive, nor does it include the numerous data sources of non-Federal organizations.

Clearly, we are learning about data sources and how to conduct secondary analyses. To this end, in June 1979 we held a conference on Federal data resources and needs with respect to research about the aged. We brought together the many people involved in the collection of Government data and in their diverse uses. We pointed out to them the problems and potentials when data collected for administrative or nonresearch purposes are used for research ends ("Demographic and Health Information for Aging Research.

Conference Summary," by C. H. Patrick and B. Gastel, unpublished report).

Cohort survival. In defining the elderly, we are studying survivors. This leads to the complicated ascertainment of differential life expectancy and cohort survival through studies of disease-specific morbidity and mortality in terms of both the surviving cohort and the potential influence upon the survivors of those who have died. We are investigating demographic and medical characteristics of institutionalized populations, particularly those in nursing homes; the nature of medical expenses and their trends; and the changing patterns of living arrangements and migration. Evaluation of medical treatments is under review, leading possibly to studies of comparative benefits, both physically and in terms of cost, of various accepted medical treatments. Environmental factors that may influence morbidity and mortality in the aged are being examined. Thus far, we are unable to find any association between local energy sources and death rates (*7–9*).

Economics and aging. Another group of studies deals more directly with the demographic shift toward an aged population and its economic ramifications. Analysis of labor force participation and the broad subject of retirement and associated health implications is a major topic. Spending patterns of the elderly are being studied in terms of health costs, housing, and other goods and services. Intergenerational income transfers and their relationship to complex issues of health, social well-being, and satisfaction will be investigated. Methodologically, we also will incorporate detailed age structure data into a multisector macro model of the U.S. economy. With this process, we can determine the impact of the aged population on demand for specific goods and services, the associated labor force shifts, the change in taxes and transfer payments, and possible consequences for government programs and alternative health policies.

Discussion and Conclusions

At the beginning of this paper, we stated that we are interested in studying health among the aged. Although many specific investigations relate to a given disease, the overriding consideration is the relationship of that disease to normal aging and to the functional capacity of the elderly person in society.

We believe that we must integrate various disciplines including at least epidemiologists, demographers, economists, psychologists, and sociologists. We are aware that we are not the first to express these high-sounding intentions although we are among the first at NIH to attempt this within the framework of medical epidemiologic research. As a measure of our sincerity, our senior staff now consists of a medical epidemiologist, a PhD demographer economist, a PhD epidemiologist, and a PhD sociologist. Having thus erected a potential Tower of Babel, we are committed to such quantitation-defying concepts as health, quality of life, lifestyle, social support, and to research within the confines of the Privacy Act, Freedom of Information requests, regulations, and mountains of paperwork for Office of Management and Budget forms clearance. We believe that multidisciplinary approaches really do not have a good track record and that usually the dominant team member rules with his discipline. In fact, it is quite possible that the finer the talent, the more individualistic the approaches. We do believe that, in the past, communication has been poor among the various disciplines alluded to and that parochialism has flourished. As yet, we have no answers and no great success stories to tell. A subject as complex as health among the elderly demands a variety of approaches and a maximum of integration of resources and data.

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