THE LONGITUDINAL STUDY OF FAMILIES AS A METHOD OF RESEARCH

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THE peculiar quality of a study of a population of families over a period of years is that it affords the opportunity to obtain information which is dynamic. Thus it is a valuable method suitable for use in many fields.

The growth and decline of the family as a biologic unit can be described. In the field of population, growth is depicted by the number of children born to a given union in relation to the date of marriage and the age of husband or wife. However, the size of the family is dynamic for reasons other than growth. It is subject to depletion over a period of time by death of members, and also to dissolution by divorce or separation from the family of one spouse.

The growth of the family as a social unit can also be described if measurable characteristics of such growth can be developed. Also, the family can be described as an economic unit and since changes in this respect provide fairly objective data, it is possible to note them over a period of time.

In the field of anthropology, Kluckhohn has suggested that contemporaneous observation of persons over a period of time may yield even better and more reliable information concerning culture and personality than is obtained from retrospective life histories (1).

An adequate description of a population of families is more difficult than is a description of a population of persons. The family is complex and is constantly undergoing change. An extreme example of its complexity may be cited. The mobility among a sample of Negro tuberculous households in Upper Harlem, New York, was studied. This investigation included a description of the movement of persons into and out of the households. The households were composed of the immediate

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family unit, that is, husband, wife and their children, other relatives, and lodgers. Members of the immediate family moved at the rate of 17 per 100 persons per year, other relatives at the rate of 46 per 100 per year, and lodgers in these families moved on the average twice a year; their rate was 196 per 100 persons per year (2).

The longitudinal study of a population composed of families was originated by Sydenstricker. He described the purpose of the study made over a period of twenty-eight months (December, 1921–March, 1924) in Hagerstown, Maryland, as follows: "This record, the first of its kind as far as we are aware, was regarded as desirable in order to give a picture of the sickness *incidence* in a general population over a sufficiently long period of time to distinguish it from sickness prevalence as ascertained at a given instant in time by the cross section method" (3).

In studies of diseases of long duration, Frost introduced a new concept of epidemiology—that studies of such diseases must be carried out over a long period of time (4). For example, it is characteristic of tuberculosis that the time intervening between exposure to infection and the development of clinical symptoms of disease is much longer than in the acute communicable diseases. Persons who have had familial exposure should be followed over a considerable period of years if incidence of disease among them is to be obtained.

It is apparent that the longitudinal observation of families was introduced in order to study disease. As a method of study, however, it has many other potentialities. It can be used in the study of health.

Reed has emphasized the possibility of studying "health" instead of disease provided that suitable gradations or measurements with respect to health can be determined. At the Fund's Annual Conference in 1947, Reed said "A definition of positive health . . . . is a problem calling for research in physiological fields; some of the work being done in geriatrics at the present time will be helpful in this direction, but a real solution will come when we have better concepts and better knowl-

edge of the development of the human being as a functioning organism. Rather than a seeming separation of pediatrics from geriatrics, we need knowledge as to the growth and development of physiological processes as we proceed from infancy to old age. This knowledge may give us some of the yardsticks necessary for an evaluation of 'positive health' and may help us to lay down objectives in this field" (5).

The concept of long-term field studies of the child in his natural environment is fairly new. An important study of this sort is being conducted by Sir James Spence in Newcastle Upon Tyne. The objective of the investigation was to study 1,000 infants from the day of their birth through their 8th year of life. According to Sir James Spence, this study of 1,000 infants inevitably became a study of 1,000 families. The records which are being accumulated show how 1,000 families drawn from all social classes live, how they react to the problems of life, how they avail themselves of the health services, how the children are nurtured in body and mind, what their activities are, and the relation of these to others in the family. This approach to the study of child life holds great promise of valuable results (6).

To return to the use of longitudinal observation of a population as a method of study of disease, I wish to place emphasis upon the unique possibilities which this method affords in the study of chronic conditions. One of these possibilities is the observation of incidence of such diseases in the population. Illnesses of a chronic nature have a low incidence, that is, recognition of newly-diagnosed cases, in comparison with their prevalence at any given time. For example, in the population observed in the Eastern Health District of Baltimore, the annual incidence of new diagnoses of "major chronic" illness was 23.6 per 1,000 person years compared with a prevalence of 178 per 1,000 person years (7). It is apparent that if prevalence is not considered, incidence of new cases alone will not reveal the true state of the population with respect to the presence of chronic disease in it.

The incidence or attack rate of chronic disease, however, is of particular interest to many workers in the field of health and especially to the epidemiologist. Observation of cases from the time of first recognition or first diagnosis enables more accurate study of the course of the disease in time and of the effect of such illness upon the family than is possible from retrospective histories. Furthermore, cases prevalent in the population at a given time cannot be used for this type of study since they represent survivors only. Close observation of a population over a one-year period is not a sufficient time for gauging accurately disease and conditions which develop slowly and occur at a relatively low rate.

Incidence of Chronic Conditions

Data from the morbidity study in the Eastern Health District of Baltimore over the five-year period June, 1938 to May, 1943 are presented to illustrate various ways of expressing incidence.

Briefly, the method of the study was as follows: Families living in thirty-four city blocks were visited at monthly intervals to obtain a record of illness of their members. In seventeen of the thirty-four city blocks the families were visited over a period of five years; in the other seventeen, visiting was continued for three years. Careful inquiry was made concerning members of the family who were in institutions for the mentally ill, for the feeble-minded, for the tuberculous, and for other chronic conditions requiring institutional care.

The instructions for the use of the family visitors contained a list of the more common chronic diseases about which special inquiry was to be made. This special information included data concerning onset of the first symptoms of the disease, their nature and date, the date first diagnosed, and whether the diagnosis was made by a private physician, at a clinic, or at a hospital. Illnesses that were reported as chronic were asked about on each subsequent visit to the family. Inquiry was made concerning the amount of discomfort or disability suffered from the condition since the last visit and the amount and nature of medical care received for it.

The causes of chronic illness as reported by the family informants were submitted to attending physicians for confirmation or correction. The cases which had clinic attendance and hospital admissions were also checked against the records of the clinic or hospital where the service was given. The only exception to this procedure was for cases hospitalized outside the City of Baltimore.

The chronic conditions included in this analysis are those classed as "major." They include: heart disease, hypertension or high blood pressure, arthritis, tuberculosis, diabetes, chronic nephritis, rheumatic fever, varicose veins, chronic gall-bladder disease, syphilis, malignant neoplasm, peptic ulcer, toxic goiter, epilepsy, mental deficiency, psychoses and psychoneuroses, and other important but relatively rare conditions, such as Parkinson's disease, cerebral palsy, and multiple sclerosis.

When a population of families is first surveyed for illness the chronic diseases usually form the major proportion of the total illnesses present at that time. In the study in the Eastern Health District of Baltimore, from 60 to 70 per cent of the total illnesses reported as present at the time of the first visit were those of a chronic nature. These were all conditions which had their onset prior to observation of the family and cannot be considered as incident within the period of observation. Information concerning the presence of persons in the population with chronic disease which had its onset before observation makes it possible to separate these persons from those at risk of development of such conditions during subsequent observation. Thus we have two classes of population—those who reported the presence of chronic illness and those who considered themselves as free from a chronic condition at that time. There are also two classes of families—those in which one or more persons were reported to have a chronic illness and those which reported their members as having no chronic condition.

This fact should be stressed. Incidence of chronic disease as expressed in this analysis is the incidence of a new or first diagnosis or report of such disease in the observed population at

risk. Quite different results would no doubt be obtained if all persons in the sample population had frequent medical examinations to detect the presence of chronic conditions. However, it is believed that incidence which includes only persons sufficiently ill to obtain a diagnosis of the illness has value and in fact it is the only measure of incidence we have at the present time.

Table 1. Annual incidence of new diagnoses of chronic disease.

Diagnosis Class	Rate Per 1,000 Population (20,832 Person Years)
Total	23.6
1. Arthritis	4.6
2. Heart Disease	5.1
3. Hypertensive Vascular Disease and Arteriosclerosis	3.3
4. Psychoneurosis and Nervousness	2.2
5. Rheumatic Fever	1.2
6. Varicose Veins	0.6
7. Gall-Bladder Disease	1.1
8. Diabetes	0.5
9. Mental Deficiency	0.0
10. Psychosis	0.4
11. Tuberculosis	0.9
12. Syphilis	0.3
13. Neoplasm (Malignant)	1.2
14. Peptic Ulcer	0.5
15. Goiter (Toxic)	0.1
16. Other Chronic Diseases	1.8

The annual incidence of new diagnoses of major chronic disease by type is of interest. Table 1 shows these data for the total sample population in the thirty-four city blocks. The population for this table is composed of 20,832 person years. Heart disease, type No. 2 on the table, occurred most frequently. If all circulatory disease be considered, types 2 and 3, the rate was 8 per 1,000 per year, a rate almost double that for arthritis. The incidence of new cases of psychoneurosis and nervousness was 2 per 1,000 per year. Rheumatic fever, type No. 5, and malignant neoplasm, type No. 13, had an annual frequency of slightly more than 1 per 1,000 person years.

One interesting point brought out by this table is the fact that, excepting arthritis and psychoneurosis and nervousness, the leading chronic illnesses which appear in incidence of new cases are also leading causes of death.

During the first year of the study there was in the seven-

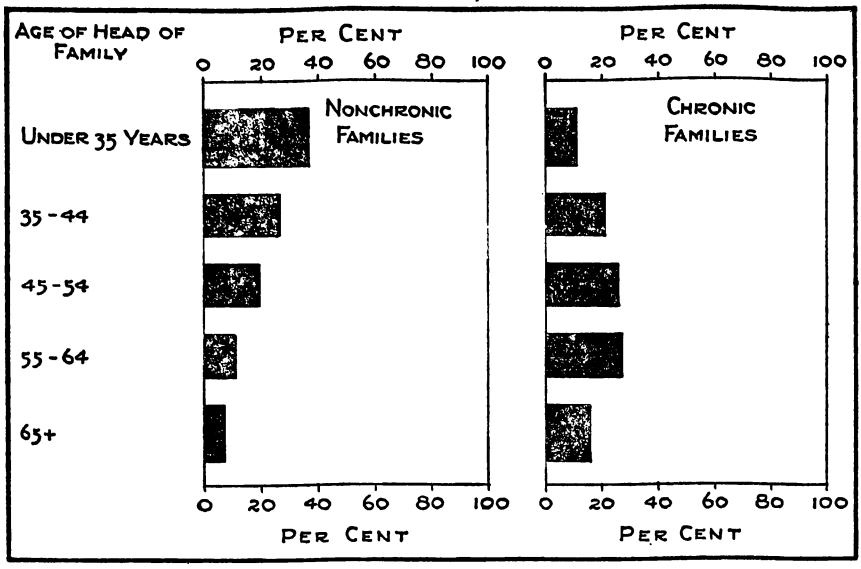

Fig. 1. Distribution of "nonchronic" and "chronic" families according to the age of the head of the family.

teen city blocks observed for five years a total of 951 families. These families must have been observed two months or longer to be included in the study. 305 or 32 per cent were classed as "chronic families," that is, families in which one or more members reported the presence of a major chronic condition. Figure 1 shows the distribution of the families according to the age of the head. The left-hand side of the chart shows the "nonchronic" families and the right-hand side those which reported one or more cases of chronic illness when first observed. There is a striking difference between the two groups. The majority of the "nonchronic" families was in the younger age groups; addition of the first and second bars shown in the chart indicates that in 63 per cent the head of the household was under 45 years of age. In the "chronic" families, only 31 per cent of the families were in these two age groups.

Incidence of Persons With First Diagnosis. One way of presenting incidence of chronic disease in the longitudinal study is to show the annual rate in each year at which persons from the nonchronic population are transferred to the

population classed as having chronic disease. These data are based on the seventeen city blocks observed for five years and are shown in Table 2. Here the population (Column 3) is composed of persons who have not had a diagnosis of a major chronic disease or condition. The population is expressed in person years. The rates from the first to the fourth year range from 17 to 22 per 1,000 in the population at risk of such a diagnosis. There was a sharp decline in the fifth year. The incidence of persons newly diagnosed in that year was less than half the rate noted in any of the preceding years. Evidently by the fifth year some selection in the observed population had taken place.

Incidence of New Diagnoses of Chronic Disease. A second way of presenting incidence of chronic disease in the longitudinal study is to show the incidence of new diagnoses of chronic conditions. Here the population at risk includes not only those who were reported as free of any chronic condition but also those who at the beginning of observation were reported to be affected by the presence of chronic illness. The population in the latter group are at risk of developing

Table 2. Incidence of first diagnosis of chronic disease among persons at risk.

Study Year	Annual Rate Per 1,000 Person Years	Number of Persons With First Diagnosis of Chronic Disease	Number of Person Years at Risk
First Study Year (6,1938-5,1939)	20.9	56	2,682
Second Study Year (6,1939-5,1940)	16.9	44	2,600
Third Study Year (6,1940-5,1941)	21.9	55	2,516
Fourth Study Year (6,1941-5,1942)	18.9	45	2,376
Fifth Study Year (6,1942-5,1943)	8.1	18	2,217

a different and unrelated chronic condition. For example, a person with hypertrophic arthritis has the risk of developing heart disease or cancer as do others of the same age and sex in the general population. When the rate of development of arthritis is considered, those known to have arthritis are excluded. This procedure applies to each type of chronic illness.

Table 3 shows the total incidence of new diagnoses (Column 2) and the incidence of new diagnoses among persons previously reported as free of any chronic illness (Column 1). These rates are presented in the same table to illustrate the fact that consideration of all new diagnoses does not distort the incidence rates. The rate of new diagnoses is composed chiefly of instances of persons with a first diagnosis of chronic illness. However, it should be emphasized that incidence among nonchronic persons only does not give a true picture of the incidence of disease when the total community is considered. Here the rates in the first four years range from 22 to 25 per 1,000 person years compared with rates of 17 to 22

Table 3. Incidence of first diagnosis of chronic disease among persons and of new diagnoses.

Study Year	Rate Per 1,000 Person Years		Number	
	New Persons With Chronic Disease	New Diagnoses of Chronic Disease	New Persons With Chronic Disease	New Diagnoses of Chronic Disease
First Study Year (6,1938-5,1939)	20.9	22.6	56	68
Second Study Year (6,1939-5,1940)	16.9	21.6	44	63
Third Study Year (6,1940-5,1941)	21.9	25.0	55	71
Fourth Study Year (6,1941-5,1942)	18.9	22.4	45	60
Fifth Study Year (6,1942-5,1943)	8.1	12.3	18	31

per 1,000 person years among those with a first diagnosis of chronic disease.

The consideration of the incidence of new diagnoses, both in the nonchronic and chronic populations is important because, in community planning for adequate facilities for care and treatment of chronic disease, it is advantageous to know the size of the problem in terms of the number of diagnoses rather than solely on the basis of persons affected. For example, the patient with arthritis and hypertensive vascular disease may need treatment for both conditions.

Incidence of Family Units With a First Diagnosis of Chronic Disease. The longitudinal study of families affords a third expression of incidence, that is, the rate at which family units were affected by a first diagnosis of chronic illness in one of their family members. The population at risk is composed of family units reported to be free of chronic illness at the beginning of observation; that is, no member was reported as affected.

Table 4 shows for each study year the per cent of the nonchronic families which had a first diagnosis of chronic disease

Table 4. Per cent of nonchronic families with a first diagnosis of chronic disease in a family member.

Study Year	Number of Families Present in Each Year	Families With First Diagnosis of Chronic Disease in Each Year	Per Cent With First Diagnosis of Chronic Disease in Each Year
First Study Year (6,1938-5,1939)	646	31	4.8
Second Study Year (6,1939-5,1940)	611	23	3.8
Third Study Year (6,1940-5,1941)	562	28	5.0
Fourth Study Year (6,1941-5,1942)	534	24	4.5
Fifth Study Year (6,1942-5,1943)	450	11	2.4

in a family member. The per cent which became affected ranged from 4 to 5 during the first four years of the study. There was a sharp decline in the fifth year. Only 2 per cent of the 450 families observed in that year reported a first diagnosis of chronic illness in one of their family members.

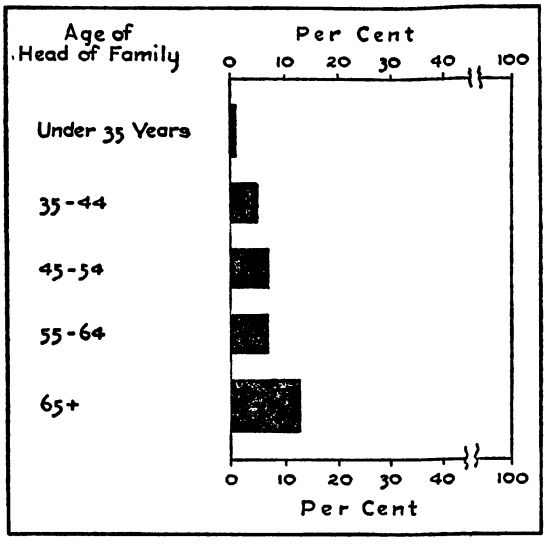

Fig. 2. Per cent of "nonchronic" families, according to the age of the head of the household, where a diagnosis of chronic disease was made for the first time.

Figure 2 shows for the first study year the per cent of the nonchronic families in each group—according to the age of the head of the family—where during that period a diagnosis of chronic disease was made for the first time. Young families (head under 35 years of age) yielded the smallest proportion, 1 per cent, of their total and those where the head of the family was 65 years of age or older, the highest proportion, 13 per cent. This is as expected. However, it is of interest that from 5 to 7 per cent of the families in the other three age groups had a member who brought them for the first time into the category "chronic disease families." Also, it is noteworthy that no age group was entirely exempt from the risk of producing families with a member who developed a chronic condition to the point that it was reported as illness.

In the new chronic families, heart disease was the most frequent diagnosis; those next in order were arthritis, hypertensive vascular disease, rheumatic fever, cancer, and psychoneurosis.

It is certainly apparent that family units with no chronic disease among their members when first observed became

affected at a fairly regular rate, year by year. The longitudinal study offers an unusual opportunity to study these families which have been observed with equal care before and after the advent of a diagnosis of chronic disease in one of their members. For example, in 45 per cent of the new chronic families, the head of the household was the patient. It will be of interest to learn the effect of a major illness upon all of these family units and especially those where the patient had a great responsibility in that unit.

The incidence among persons with a first diagnosis of chronic illness, the incidence of total new diagnoses and of new families affected all showed annual rates which were consistent in their general level during the first four years of observation of the population in the seventeen city blocks. None of the variations in incidence noted in that period were statistically significant. The consistency of these rates over a period of time supports the belief that they express a reality, that is, the rate at which persons become so aware of illness that they obtained a diagnosis or reported it as an existing condition.

From the data presented, it is evident that by the fifth year of the study some sort of selection had taken place in the population being observed for illness. There was a significant decline in the incidence of new persons with a first diagnosis or report of chronic disease, and of new diagnoses in the fifth year compared with any previous year. There was also in that year a significant change from the other years with respect to the proportion of families previously classed as nonchronic which for the first time reported a member as having an important chronic illness.

One form of selection may arise from refusal of the family to cooperate in the study. Table 5 shows in each year the per cent of the total families which refused to cooperate. The data are shown for families classed as nonchronic and for those classed as chronic. In both groups of families, refusal to cooperate occurred most frequently in the first study year.

About 5 per cent in each group were lost to the study in that year. The proportion lost to the study declined sharply in the second and third years compared with the first year. In the fourth and fifth years the proportion who wished to be dropped from the study increased and reached the level of the first year. It is important to note that in each year a smaller proportion of the families with chronic disease refused to cooperate than was true of families with no person in them who reported a major chronic condition. The difference between the two groups of families with respect to the proportion which refused cooperation is statistically significant in the third year, in the fourth year, but not in the fifth year.

Table 5. Per cent of families present in each study year which refused to cooperate in the study.

Study Year	Nonchronic Families	Chronic Families
First Study Year (6,1938-5,1939)	5.4	4.9
Second Study Year (6,1939-5,1940)	3.3	1.2
Third Study Year (6,1940-5,1941)	1.8	0.3
Fourth Study Year (6,1941-5,1942)	4.5	1.4
Fifth Study Year (6,1942-5,1943)	5.3	3.6

Some of the other possibilities for the study of chronic illness which the longitudinal observation of a population affords may be mentioned briefly. It is of interest to learn how chronic illness manifests itself over a period of time. Is the risk of disability from chronic disease greatest at the time of first diagnosis and does that risk diminish with time? Persons found to be diabetic and those who have survived their first attack of coronary disease may be cited as those where the risk of disability may decrease with time. What proportion of the total adjust and learn how to live with their chronic conditions? Or is the disease of such a rapidly progressive nature that the risk of disability increases with time? Some types of cancer may illustrate diseases in this

category. Also, disabling episodes of chronic illness can be related to the total observed population in order to express the general risk of such illness. It may be that some of these questions cannot be answered in a period so short as five years. However, it will be of interest to explore the possibilities for doing so.

Family Patterns of Chronic Disease

The study of chronic illness in the Eastern Health District of Baltimore has also made it possible to investigate family patterns of disease. An index case was designated for each family with "major chronic" disease, that is, the index case was the person with a chronic condition which determined the classification of the family. In families where, at the time of first observation, there was more than one living case of "major chronic" disease, the case with the earliest onset was selected as the index person. It was then possible to learn whether other members of the family tended to have the same type of chronic illness as the index case.

During the period of study of the families in the thirty-four city blocks in the Eastern Health District, a total of 828 families reported one or more cases of chronic illness among their members. The shortest possible period of observation of these families was two months and the longest possible period was five years. Excluding the index case, these families contained 2,842 people. The presence of some major chronic condition was reported for 15 per cent of these family members.

To illustrate the family pattern of chronic illness, all families in which there was a person designated as ill because of psychoneurosis or nervousness are compared with the total universe of chronic-disease families. There were 90 such families. The index case in each of these families was an adult 20 years of age or older who was diagnosed as psychoneurotic or who reported chronic nervousness.

It should be explained that patients do not report themselves as having a psychoneurosis. This term is not a part of

their vocabulary. They report their illness in terms of complaints or symptoms. The diagnosis "psychoneurosis" comes from the attending physician. Sixty-six of the 90 index cases, or 73 per cent, had such a diagnosis. The remaining 24 patients complained of chronic nervousness but were not seen by a physician because of their complaint.

The complaints of the 66 diagnosed by a physician were as follows:

Nervous with:

Indigestion	Giddiness and dizzy spells
Cardiac symptoms	Stuttering
Menopause	Loss of voice
Low blood pressure	Nervous throat
High blood pressure	Lump in throat
Headache	Melancholy
Shortness of breath and choking	Worry
Weakness and run down	Itching all over

The complaints of the 24 not seen by a physician were similar to those who received a diagnosis.

In a study of the complaint of nervousness and the psychoneuroses in the population of the Eastern Health District, made by Lemkau and his associates, it was concluded that "the lay term nervous is used to cover a multitude of psychiatric conditions, but when treated as a residual group, after the removal of known psychotics and mental defectives, this group corresponds in sex and race distribution patterns to the group of adult cases diagnosed psychoneurosis or as having neurotic traits" (8). This was considered as sufficient reason for including nervous cases in a group called the "adult neurotic group." Therefore, in this analysis the 24 index cases with chronic nervousness were included with the 66 who had the diagnosis psychoneurosis.

This table (Table 6) compares the per cent of persons with specific diagnoses in the 90 families, index case psychoneurosis or chronic nervousness, and those in the total 828 families, the

Diagnosis Class	Index Case Psychoneurosis (90 Families)	Index Case Major Chronic Condition (828 Families)	Ratio Column 1 / Column 2
Total	26.98	14.80	1.82
1. Mental Disorder or Mental Deficiency	3.81	0.32	11.91
2. Mental Retardation	0.32	0.14	2.29
3. Psychoneurosis or "Nervousness"	1.90	1.48	1.28
4. Rheumatic Fever	2.54	1.09	2.33
5. Heart Disaese	4.76	2.64	1.80
6. Hypertensive Vascular Disease and Arteriosclerosis	3.81	1.72	2.22
7. Diabetes	0.63	0.35	1.80
8. Arthritis	2.86	2.67	1.07
9. All Other Chronic Diseases	6.35	4.39	1.45

Table 6. Per cent of persons with a major chronic condition in two groups of families (index cases excluded).

universe from which the 90 families were drawn. Column 3 indicates the ratio of the per cent of persons affected in the families, index case psychoneurosis, to those affected in the total 828 families. All index cases have been excluded from both groups. It certainly is apparent that persons with chronic illness are more highly concentrated in these 90 families than in the total universe of families from which they were drawn. The differences in the per cent affected in these families and in the total 828 families are highly significant.

An examination of the 90 families with regard to socio-economic factors revealed no important difference between them and the 828 families from which they were drawn. They were similar with respect to size, to moving, crowding, income, home ownership, and education of persons 20 years of age and older.

From the etiological point of view, it may be that a concentration of chronic conditions among members of families tends to produce psychoneuroses among some of those not otherwise affected. In other words, the stress upon the family brought about by illness may be so great that responsible mem-

bers of the family may be affected to the degree that they seek an escape in illness. However, genetic and constitutional factors in these families have not been studied and it may be profitable in future investigations to consider such factors.

One of the most important potentialities of the study of families over a period of time is the determination of a better understanding of family attitudes towards health and towards illness. Late diagnosis of chronic illness is a problem difficult to cope with and we have been prone to consider that it is in great part due to an economic barrier between the patient and the procurement of medical care. However, there are other barriers. The psychological barrier between the knowledge of the presence of symptoms and the procurement of a diagnosis is real, very real. A person may feel under par as to his health but he may wish to avoid as long as possible the knowledge as to why he is not well.

Experiments which are now under way, The Health Insurance Plan of Greater New York and The Family Health Maintenance Plan, will no doubt increase our understanding of family attitudes towards health and sickness. In these experiments the economic barrier to procurement of medical care has been removed and those in charge are doing their utmost to remove the psychological barrier through a campaign of education for better health through use of medical service. Their results will need to be carefully measured. They will be eagerly awaited.

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