Comparisons of Various Methods of Estimating the Prevalence of Chronic Disease in a Community—The Hunterdon County Study

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The analytic reader will be impressed with the solid objectivity maintained throughout this study. It is revealed nicely in the final comment of the authors ". . . for chronic disease, household interviews may be expected at best to provide minimum estimates of morbidity."

✢ This is a preliminary report upon a few observations of methodological significance to morbidity surveys. The findings presented have resulted from a survey of the prevalence and needs of individuals with illness and disability in an essentially rural population. It was conducted by the Hunterdon Medical Center in Hunterdon County, N. J., during a three-year period, 1952–1955. The original plans for two such surveys—one urban and one rural—were developed for the Commission on Chronic Illness when one of the authors was director.*

The Hunterdon survey was one of the components of the long-range program of the commission which sponsored this rural study, assisted with consultation and minor financial participation, and carried out the parallel urban study in Baltimore, Md. The Hunterdon survey also was sponsored by and assisted with extensive staff participation from the New Jersey State Department of Health. A major portion of all studies and analysis of findings has been the responsibility of the National Opinion Research Center. Primary financial support was provided by the Commonwealth Fund which also made a substantial grant to the commission to enable completion of the urban survey.

The rural survey was made under the over-all direction of one of the authors † who was serving also as director of the Hunterdon Medical Center. The National Opinion Research Center participation has been guided by a senior study director.‡

The survey findings are extensive and

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will deal also with the large gap between needs, as determined by team evaluation, and actual utilization. The data currently are being assembled into a sizable report which probably will not appear in final form before early summer of 1956. However, certain methodological facts are already evident. They are selected as of particular interest, because of their relevance to our very realistic need for better epidemiologic understanding of many long-term illnesses through accurate determination of prevalence and incidence in the population at large.

In the literature our present knowledge of prevalence and incidence is an accumulation of several approaches, such as household interviews; study of physician, institutional, and organizational records; and multiple screening. Much use has been made of data provided through an interview of a lay respondent by a nonmedical interviewer in a home setting where the cooperation of the respondent has to be solicited and is voluntary. Additional information has been provided by personal health diaries and by questioning physicians who have been asked to confirm, alter, or supplement diagnoses reported by their patients in household interviews. Multiple screening of large numbers of self-selected individuals, presumably well, has yielded much data which are suggestive but difficult to evaluate.

How valid are the statements made in household interviews and by physicians named as attending the reported conditions? What volume of disabling or potentially disabling conditions is not suspected as the result of multiple screening? Can a self-administered questionnaire be distributed to a population at large and return useful but less expensively acquired data? Partial or substantial answers to such questions are emerging from the Hunterdon County and Baltimore surveys. Three sets of observations now available from the rural study are presented at this time.

Surveyed Population

Enough descriptive data will be listed here to provide an over-all picture of the population studied. Hunterdon County covers about 435 square miles stretching irregularly along the Delaware River in northern New Jersey. It is an area of farms, woodlands, small boroughs, rural townships, and a few small industries. In the 1950 census (total population 42,736) the 26 municipalities making up the county had populations ranging from 486 to 4,467 with only two of 2,500 people or more. The county seat of Flemington is located midway between New York City and Philadelphia, 50 miles in either direction, and 23 miles north of Trenton, the state capital.

The year covered by the survey as the primary study period was a year (midpoints 1951–1952) in which the county was served by approximately 25 general practitioners, 12 school and public health nurses, two small voluntary agencies (dental and tuberculosis), and a traveling mental hygiene clinic. The county had no community hospital, no health department, no diagnostic facilities, and no specialists practicing within its boundaries.

Detailed population analyses are not essential to the present report. However, by comparison with the state as a whole, Hunterdon residents were above the median age, had a higher per cent above age 65, a lower per cent of nonwhite, a slightly lower average of persons per household, a lower median number of years in school, 10 per cent less engaged in manufacturing, $700 less per family median income and 11 per cent more than the state median of families with income of less than $2,000 annually. The county population was classified as rural farm 22.9 per cent, rural nonfarm

59.5 per cent and urban 17.6 per cent. The population is not a "homogenous" grouping of rural residents.

Survey Plans

The survey steps as planned and the principle reasons for their inclusion are summarized as follows:

Phase One—The utilization of a self-administered questionnaire was undertaken for two reasons.   First to determine the usefulness of such a questionnaire, second to give every resident in the county an equal opportunity to participate in the survey and thus in the development of policies governing their local medical center based on findings of the survey.   This step required that a self-administered questionnaire for each member of each family in the county be delivered to each household and returned on a voluntary basis.   It was estimated that there were about 13,000 families with more than 43,000 members.

Phase Two—Following the use of the self-administered questionnaire, the county population was to be surveyed on an area probability sampling basis through the use of household interviews. The minimum goal for this step was to secure health histories from 4,000 family units. This number had been selected to give an estimated yield of at least 2,000 persons with "chronic" diseases. These families, since they would be representative of the county, would form the base for the next three steps of the survey.   Each interview was to encompass the entire family health history within a single folder.   It would attempt to ascertain for that family by a variety of question approaches the maximum amount of information available through a single interview about illness, disability, individuals in an institution, deaths in the family, and a variety of other details all pertaining to the 12 months preceding the interview.

Phase Three—In an attempt to ascertain the yield of information which could be secured by questioning physicians attending a rural population the third step of the survey was to be confidential communication with the physicians named by a sample of the individuals reporting illnesses. The information to be sought here was primarily diagnostic to allow for coding and comparison with findings reported through the self-administered questionnaire, personal interview questionnaire, medical examination, and multiple screening. One interesting methodological step was that half of the physicians were told what had been reported in the household interview, the other half were not.

The three approaches to ascertaining the health status of a population, as described, are not new in the field of morbidity surveys except for the completeness of the interview approach and certain "built-in" methodological studies.   Similar projects, some on a much larger scale except for the self-administered questionnaire step, have been well documented elsewhere.   The added steps made possible through the Hunterdon study are described in the following:

Phase Four—From among the total number of individuals listed in the household interviews, subsamples of stratified groups were to be drawn representing the various kinds of illness and disability reported, as well as individuals for whom no illness was reported.   A total of 1,000 individuals was to be examined.   These individuals were to be offered a complete evaluation by a team consisting of physicians, social worker, and public health nurse, together with such other consultants as they might need.   The objective of the team was to define, with every resource available, the problems facing each of these 1,000 individuals and their families; what care they should have had in the past 12 months; and what optimum

care for them would consist of in the next 12 months. The problems found were to be classified in a variety of ways in their relation to degree of disability, rehabilitative potential, preventability, employment, income, school attendance, and other community concerns.

Phase Five—From the 4,000 families not only the 1,000 individuals referred to in the preceding paragraph, but also 8,000 presumably well individuals above age 16 at time of interview were to be offered multiple screening in an effort to detect certain nonmanifest chronic diseases.

The Survey *

Of basic importance to any such survey is the voluntary participation of the public. Without cooperation from adequate numbers of individuals, both lay and professional, the results of a survey are of limited value. Prior to the five steps of the survey it was necessary to obtain clearance with appropriate groups, insure the general alerting and cooperation of the public, followed by the steps of mapping, census taking, and division of the county into 900 areas as a basis for sampling.

In summary, setting the stage for the survey involved securing approval of the Board of Trustees of the Hunterdon Medical Center, the County Medical Society, and the Public Health Advisory Committee of the Medical Center. Letters of endorsement were received from the American Medical Association, the American Hospital Association, and the State Medical Society. Five hundred school children, teachers, and other volunteers brought up to date or created large-scale maps of each of the 26 municipalities and secured a census

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* Credit by title cannot be given here to the many staff members, consultants, and volunteers who performed the survey, but all are appropriately recognized in the final report.

listing in each of 900 areas into which the county was divided by delimiting certain natural boundaries, such as roads, rivers, and railroads. More than 40 public gatherings were addressed to orient organizations to the survey. Press and radio support of the project was generous. The entire County Medical Society membership signed a statement urging the public to cooperate and this document was photostated and published by all local newspapers. Every paper serving the area carried an editorial encouraging public participation. The project was influenced by the fact that the entire county was constructively involved in the creation of the Hunterdon Medical Center to which at least 75 per cent of families had contributed and which was now conducting the survey.

With this as a background the five phases of the survey were activated in the spring of 1952 when 600 volunteers delivered questionnaires to households throughout the county. This was followed by 35 trained interviewers attempting to secure health histories during the summer from a third of the families in the county; by communication with a sample of physicians named by these families; by an intensive effort to evaluate by team approach subsamples of the stratified interviewed population; and by an invitation to go through multiple screening extended to all reportedly well people (above age 16) in the same families. This process required five months of full-scale planning and pretesting, 26 months of intensive survey work, and six months of "winding up." At least a year will be required for analysis and report writing.

The productivity of the five steps was as follows: (1) from the 43,000 individuals to whom self-administered questionnaires were delivered, 23,900 were returned (56 per cent); (2) 4,246 families (13,113 individuals) were interviewed representing 91 per cent of all sought; (3) 329 physicians (by ques-

tionnaire regarding 1,569 patients) reported conditions, 86 per cent of the physicians to whom verification forms were mailed replied, 70 per cent of the total number of forms mailed out were returned filled out by the cooperating physicians; (4) 846 individuals representing 72 per cent * of the differential probability sample sought were given a complete medical, social, and nursing evaluation; and (5) 2,679 individuals presumably well were multiple screened from the same families, representing 34 per cent of the 7,953 whose participation was requested.

Methodological Observations

Three selected methodological observations which have significance for morbidity surveys have been chosen from among many for presentation.

1. Validation of a household interview by written questionnaires sent to physicians named as having attended the reported conditions.

It has been common practice to request information from physicians named by respondents in household interviews. The physician customarily has been told that what the patient said was wrong. He has been asked to confirm or alter the patient's diagnosis and to list or even check list other conditions that were present. This procedure of telling the physician what the patient said has been questioned. Such a step has been regarded as destroying the independent nature of this way of securing morbidity data. Among other "built-in" steps, the Hunterdon study was designed to examine this question of the "contamination of criteria."

As the third step in the survey, the interview folders from a sample of interviewed families were selected for "medical verification." These were randomly divided into two groups of

equal size and simple questionnaires were prepared for each physician named as having attended the conditions reported. The questionnaires were identical except that in half the cases the physician was not advised of what the patient had reported in the household interview.

Thus, 165 envelopes containing 651 questionnaires (one for each condition) went to the 165 physicians named in half the family folders selected: these forms (Form A) included the patient's reported diagnosis. As a control, 164 physicians received 687 forms (Form B) representing the physician attended illnesses in the second half of the family folders, but were not told what had been reported in the household interviews. All physicians received identical explanatory and follow-up letters and returned the forms with approximately equal degrees of cooperation.

The returns were matched according to a code which allowed for seven types of agreement. The matching was done by a physician and a statistician working as a team and according to rules which will be described in detail in the full survey report. Table 1 summarizes the results of this part of the survey.

The most striking differences found were that when the physician was not informed of the patient's reported diagnosis his own diagnosis agreed with the patient less often but he reported new conditions more frequently. The causes for these differences cannot be documented. The data also will be analyzed further in terms of selected diseases. The implications for morbidity surveys, while not clear, deserve study.

2. Validation of household interviews by medical examination of a sample of respondents.

A total of 4,246 Hunterdon families were interviewed by 35 trained and supervised interviewers, the interviews requiring from 30 minutes to six hours and averaging about one and one-half hours. The questionnaires used inquired

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* Weighted.

Table 1—Relative Productivity of Two Types of Written Questionnaires Sent to Physicians Named in Household Interviews as Having Attended Respondent Reported Conditions

Degree of Agreement Between Patient and Physician	Form A—Physicians Informed of Diagnoses Reported by Patients		Form B—Physicians Not Informed of Diagnoses Reported by Patients	
	Number of Conditions	Comment	Number of Conditions	Comment
1. Perfect	320⎫		268⎫	
2. Close	164⎪	528 confirmed in	122⎪	441 confirmed in
3. General	27⎬	some degree	31⎬	some degree
4. Vague or remote	17⎭	= 92%	20⎭	= 75%
5. Negative statement by physician on diagnosis stated by patient	10⎫	48 not confirmed	4⎫	145 not confirmed
6. Reported by patient only	38⎭	= 8%	141⎭	= 25%
7. New condition reported by physician only	131	= 22 new conditions for every 100 patient reported conditions	292	= 48 new conditions for every 100 patient reported conditions

This table is based on a study of those forms returned by physicians. Both A and B forms were returned in approximately equal numbers—75 and 72 per cent, respectively.

for each member of the family about illness, injury, or other conditions on the day before the interview, during the four weeks preceding and during the past year. They then covered a lengthy symptoms list, persons in institutions, deaths, and a long list of diseases by name.

The 13,113 individuals were then divided into six strata, ranging from people in institutions to people with no complaints, and the six groups were sampled at differential rates for team evaluation. The goal was 1,000 examinees, the yield was 846 representing 72 per cent of all whose names were drawn. This degree of success was achieved after one and a half years of hard work. The story of recruitment of a sample for examinations is a saga in itself but cannot be recounted here.

The examinations were made in the Hunterdon Medical Center by the full-time staff, a group of accredited specialists with faculty appointments in New York University-Bellevue Medical Center. Responsibility for all studies was carried by two specialists in internal medicine and one in pediatrics. These physicians had unlimited access to laboratory and radiologic services and informal and formal consultation from the other full-time and visiting consultants. For example, a review of every eighth examination record shows that for 105 persons there were (in addition to routine pelvic examinations of adult women by the gynecologist) 95 formal consultations and 1,195 tests. Two hundred families were the subject of detailed study in the home by experienced social workers. All examinees were reviewed by the social workers and the public health nurse consultant. Finally, a team conference resulted in an extensive schedule of evaluation which is the basis for the next two comparisons with data previously secured through household interviews.

Although the survey will report in

large measure on prevalence data and needs for care, reference is made here only to some problems of measuring morbidity. These comparisons provide a substantial basis for estimating over- and underenumeration in morbidity surveys when a multi-approach questionnaire is used in household interviews.

A. Overreporting by the respondent in the household interview. (This section records how successful the team was in verifying in some degree what the lay respondents had reported to the interviewers.)

When family reported conditions are considered in 21 major classifications, the following order in proportion-of-match with clinically evaluated conditions emerges as presented in Table 2.

For convenience and ease of reference we may arbitrarily place all classifications of family reported conditions into four groups (according to over-all proportion-of-match): well-matched— 80 per cent, or higher; fairly-matched—

Table 2—Validation of Household Interviews by Medical Examination of a Sample of Respondents (Total 846)

A. Proportion-of-Match for Family Reported Conditions with Subsequent Medical Examination

Order	Classification of Condition (All Conditions Reported in Family Interview)	Per cent Matching Clinically-Evaluated Conditions (Weighted)	Total Cases Reported in Family Interview (Unweighted)
1.	Diseases of the eye	98	145
2.	Mental, psychoneurotic, and personality disorders	87	46
3.	Diabetes mellitus	85	28
4.	Rheumatic fever and heart diseases	80	166
5.	Neoplasms	75	67
6.	Other diseases of the circulatory system	65	198
7.	Diseases of the ear	63	57
8.	Diseases of the genitourinary system	61	97
9.	Allergic diseases	58	59
10.	Other impairments, including congenital	57	101
11.	Other endocrine, metabolic, and nutritional diseases	57	37
12.	Diseases of bones and organs of movement	56	138
13.	Dental and other diseases of buccal cavity and esophagus	53	127
14.	Other diseases of the digestive system	48	171
15.	Diseases of the nervous system	45	82
16.	Diseases of the skin and cellular tissue	34	74
17.	Symptoms, senility, and other ill-defined conditions	29	205
18.	Injuries and poisonings	24	62
19.	Diseases of the respiratory system	23	223
20.	Anemias and other diseases of the blood	19	33
21.	Infective and parasitic diseases	13	90
	Total	47	2,206

60–79 per cent; poorly-matched—40–50 per cent; and badly-matched—less than 40 per cent.

Under the above arbitrary limits we can say that only for diseases of the eye, mental, psychoneurotic, and personality disorders, diabetes, and rheumatic fever and heart diseases are family reports relatively "well" matched with clinical evaluation.

Acute conditions reported in the family interview cannot be expected to match clinically evaluated conditions established 20 months after the family interview. We find, therefore, relatively "bad" proportions-of-match for infective and parasitic diseases, diseases of the respiratory system, injuries and poisonings, and diseases of the skin.

Vaguely reported conditions, including symptomatic descriptions, are also relatively "badly" matched with clinically evaluated conditions. Reported anemias, too, are relatively "badly" matched.

Conditions which were characterized in the family interview by some index of seriousness, such as "keeping a person from his ordinary activities yesterday" or "leaving a handicap or defect" or "still bothering" were less likely to be overreported. Similarly hospitalized and medically attended conditions were less likely to be overreported.

Table 3

B. Proportion-of-Match for Conditions Found by Medical Examination of 846 People with Conditions Previously Reported by Family (for Conditions Believed by Clinician to Have Been Present in Period Covered by Family Interview)

Classification of Condition	Per cent Matching Family Reported Conditions (Weighted)	Total Conditions Found by Clinical Evaluation (Unweighted)
Diabetes mellitus	64	30
Diseases of the ear	56	83
Allergic diseases	54	51
Heart diseases and rheumatic fever	39	288
Anemias and other diseases of the blood	39	8
Diseases of the respiratory system	38	108
Diseases of the nervous system	37	85
Injuries and poisonings	32	83
Other diseases of the digestive system	31	180
Diseases of bones and organs of movement	30	197
Other diseases of circulatory system	26	320
Mental, psychoneurotic, and personality disorders	22	153
Diseases of the eye	20	470
Infective and parasitic diseases	16	73
Diseases of skin and cellular tissue	20	76
Dental and other diseases of buccal cavity and esophagus	11	192
Diseases of genitourinary system	11	230
Other impairments, including congenital	10	66
Neoplasms	10	151
Other endocrine, metabolic, and nutritional diseases	6	183
Symptoms, senility, and other ill-defined conditions, and special examinations	4	82
Total	22	3,109

Table 4—Comparison of the Total Number of Conditions Reported in Family Interviews with the Total Number of Conditions Found by Medical Examination of a Sample of 846 Respondents (Unweighted Data)

Order	Classification of Condition	Number Reported	Number Found	Difference
1.	Diseases of the eye	145	470	+ 325
2.	Mental, psychoneurotic, and personality disorders	46	153	+ 107
3.	Diabetes mellitus	28	30	+ 2
4.	Rheumatic fever and heart disease	166	288	+ 122
5.	Neoplasms	67	151	+ 84
6.	Other diseases of the circulatory system	198	320	+ 122
7.	Diseases of the ear	57	83	+ 26
8.	Diseases of the genitourinary system	97	230	+ 133
9.	Allergic diseases	59	51	− 8
10.	Other impairments, including congenital	101	66	− 35
11.	Other endocrine, metabolic, and nutritional diseases	37	183	+ 146
12.	Diseases of bones and organs of movement	138	197	+ 59
13.	Dental and other diseases of buccal cavity and esophagus	127	192	+ 65
14.	Other diseases of the digestive system	171	180	+ 9
15.	Diseases of the nervous system	82	85	+ 3
16.	Diseases of the skin and cellular tissue	74	76	+ 2
17.	Symptoms, senility, and other ill-defined conditions	205	82	− 123
18.	Injuries and poisonings	62	83	+ 21
19.	Diseases of the respiratory system	223	108	− 115
20.	Anemias and other diseases of the blood	33	8	− 25
21.	Infective and parasitic diseases	90	73	− 17
	Total	2,206	3,109	

B. Underreporting by the respondent in the household interview. (This section records what proportion of conditions discovered by team evaluation had been reported previously in the household interview.)

As shown in Table 3, less than one-fourth (22 per cent) of the conditions found by clinical evaluation was matched with conditions reported in the family interview. This proportion-of-match is for clinically evaluated conditions believed by the examining clinician to have been present in the period covered by the family interview and which presumably should have been reported.

The proportion-of-match for clinically evaluated conditions varied greatly by type of condition. For diabetes, one out of three cases found by clinical evaluation was not reported in the family interview. Six out of 10 cases of clinically evaluated heart conditions were not reported in the family interview. Three-fourths of the clinically evaluated "mental, psychoneurotic, and personality disorders" were unreported in the family interview. Nine out of 10 "neoplasms" established by clinical evaluation were unreported in the family interview.

It was felt that this rather low proportion-of-match was perhaps not entirely attributable to failure of the family interview respondent to report known conditions or even to ignorance of existing conditions, but that a substantial part of the discrepancy might

be attributed to the thoroughness of the clinical examination and the meticulousness of the clinicians in their reporting of minor and unimportant conditions. In order to confine the analysis to the more significant conditions, a comparison was made between clinical findings and family reports for those conditions only which clinicians considered to be ". . . currently or potentially disabling. . . ." or which had been disabling in the year preceding the clinical examination. Two-thirds of the clinically evaluated conditions believed to have existed in the family interview year were considered by clinicians as "disabling" in the sense described.

The over-all proportion-of-match for "disabling" clinically evaluated conditions was not importantly higher than for "nondisabling" clinically evaluated conditions (24 per cent as against 18 per cent).

Finally, Table 4 is presented to compare the total number of conditions reported in family interviews for 846 individuals compared with what was found in medical examinations. (The reader is cautioned that this is an unweighted table and cannot be used for computation of rates or percentages.)

Comment

The data presented here are subject of course to much explanation which will be included in the final report. While these observations are brief (and much more detailed analyses will be reported subsequently), they are thought-provoking with respect to the problem of securing accurate morbidity data. Surveys such as the Hunterdon and Baltimore studies are expensive, time-consuming, and difficult. No attempt is made in this brief report to discuss epidemiologic studies of long-term illness, but the problems of accurate measurement of prevalence and incidence are evident and will require large-scale planning and financing for their further elucidation.

The data at hand suggest that for chronic disease household interviews may be expected at best to provide minimum estimates of morbidity.

Labeling Salicylates for Safety

The U. S. Food and Drug Administration recently issued a statement of policy with regard to labeling salicylates in order to prevent their misuse, particularly by children. Drug manufacturers are asked to use conspicuous package warnings that such drugs should be kept out of reach of children. The six-month period allowed for modification of present labeling ends April 15, 1956.

The FDA ruling was published in the Federal Register of October 15, 1955.