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ABSTRACT

This study of chronic illness in the home originates in theoretical and practical questions posed by physicians, nurses, and biometricians. The study covers the following elements: The research plan, the patient sample, providing continued care, interviewing, classification of disease and mental status, effect of treatment program, classification of social factors, and interpretations. (7) Methods include statistical methods, evaluation schedule, and intake and outcome variables. (CK)



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# EFFECTS OF CONTINUED CARE:

## *A Study of Chronic Illness in the Home*

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## CONTENTS

	<i>Page</i>
Preface . . . . .	vii

### PART I

#### The Plan, Elements, and Results of the Study

Chapter I. Introduction . . . . .	1
Chronic Disease in American Society . . . . .	2
Home Health Services After Rehabilitation . . . . .	3
The Research Approach and Research Questions . . . . .	4
Chapter II. The Research Plan . . . . .	8
Research Design . . . . .	8
Study Intake . . . . .	10
Interval Observations . . . . .	11
Deaths . . . . .	12
Terminal Observations . . . . .	12
Organization of the Staff . . . . .	12
Data Collection . . . . .	13
Chapter III. The Patient Sample . . . . .	16
The Hospital . . . . .	16
Sample Selection . . . . .	17
Age . . . . .	18
Sex . . . . .	18
Disease . . . . .	18
Physical Disability . . . . .	20
Socioeconomic Status and Function . . . . .	21
Social Interaction . . . . .	23
Social Deprivation . . . . .	24
Psychological Characteristics . . . . .	25
Chapter IV. Providing Continued Care . . . . .	28
The Visiting Nurse Association (VNA) . . . . .	28
Service by Visiting Nurses in the Research Program . . . . .	31
Extent of Nurse Follow-Ups (Examples) . . . . .	43

	<i>Page</i>
Chapter V. Interviewing and Measures . . . . .	46
Interviewing . . . . .	46
Frequency and Completeness of Interviews . . . . .	47
Measures . . . . .	49
Measures of Physical Function and Injury, and Measures at Death . . . . .	50
Social and Economic Measures . . . . .	50
Psychological Measures . . . . .	51
Measures of Care . . . . .	52
Chapter VI. Classification of Disease, Disability and Mental Status at Intake . . . . .	54
Classes Based on Principal Clinical Diagnosis . . . . .	56
Classes According to Disease-Disability Profiles . . . . .	56
Classes Based on Indicators of Major Chronic Conditions . . . . .	57
Chapter VII. Effects of Treatment Program: All Patients and Subgroups by Disease, Disability and Mental Status . . . . .	59
Areas of Measurement . . . . .	59
Outcome in Terms of Function, Injury, and Mortality . . . . .	60
Outcome in Terms of Use of Services . . . . .	64
Chapter VIII. Classification of Social Factors for the Study . . . . .	68
Identifying Social Characteristics at Intake . . . . .	68
Social Interaction at Intake . . . . .	69
Social Deprivation at Intake . . . . .	69
Chapter IX. Effects of Treatment Program: Subgroups by Age, Sex, and Social Characteristics . . . . .	71
Outcome in Terms of Function, Injury, and Mortality . . . . .	71
Outcome in Terms of Use of Services . . . . .	73
Chapter X. Interval Results . . . . .	76
Unbiased Interval Results . . . . .	76
Interval Results Subject to Possible Bias . . . . .	79
Chapter XI. Interpretations . . . . .	83
Observation and Interaction Effects . . . . .	83
Effects of the Nursing Program . . . . .	87
 <b>PART II</b> <b>Methods</b>	
Chapter XII. Statistical Methods . . . . .	95
The Experimental Design . . . . .	95
Experimental Effects . . . . .	96

	<i>Page</i>
Intake Classes and Effectiveness of P indomization . . . . .	98
Validity of the Experimental Groups . . . . .	100
Outcome Classes . . . . .	102
Chapter XIII. Evaluation Schedule, Study Forms and Supplementary Definitions . . . . .	106
Chapter XIV. Intake and Outcome Variables . . . . .	153

**APPENDIX**

Statistically Significant Treatment Effects at End of Study . . . . .	164
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## PREFACE

In September 1961, a group of doctors and nurses met at Abington House (formerly the Benjamin Rose Hospital) in Cleveland to plan a controlled study of the effects of public health nursing on the welfare of patients discharged from a chronic disease rehabilitation hospital. Three currents of interest converged at that meeting, each of which contributed to the purpose and the final form of the study. Physicians, nurses, and biometricians formed a steering committee which offered different professional viewpoints and personal experiences. Together, the group reviewed the relatively small number of related studies which had been published to that date. From this background, the experiment reported in this book was developed, namely, a controlled study of the outcome of a sustained program of home nursing service for patients discharged from a chronic disease rehabilitation hospital.

For six years prior to the present project, Abington House had been the setting for a series of "Multidisciplinary Studies of Illness in Aged Persons". Faculty members of Case Western Reserve University School of Medicine started these studies in 1954 with the recognition that objective and tested measures of function which could be used in the chronological study of chronic illness, though increasingly needed, were almost nonexistent. A sequence of continuing long-term observations on patients with strokes and hip fractures, later expanded to include patients in nursing homes and in a home care program, was undertaken in order to develop and test such measures. Many specific observations, contributed by members of several health professions involved in caring for these patients, were systematically sifted and correlated in the search for reliable and sensitive measures of function. Two useful indices, one of Independence in Activities of Daily Living (*J.A.M.A.* 85:914-919, 1963) and one of Independence in Socioeconomic Functioning (*J. Chron. Dis.* 13:453-464, 1961), had been developed and were available for use in the present study. Since the "Multidisciplinary Studies" had been conducted primarily on patients in and discharged from Abington House, a great deal of information was available about this particular population. Methods for the collection of information about these patients were well developed and in current use, and a staff of experienced research assistants was available.

Abington House, a unit of University Hospitals of Cleveland, is a small hospital that provides rehabilitation and hospital services for patients with chronic illness. The care of older persons is emphasized. Staff of the hospital had a particular interest in the care of chronically ill patients after their discharge from the hospital. Just prior to the present study, efforts had been made to bring discharged patients back to a clinic at the hospital for follow-up evaluation. This ambulatory program proved feasible for only half the patients. The other half could not return because of physical disability and transportation problems or would not because they or their

physicians did not consider that such reevaluation was needed. Many of the patients who could not return to the hospital were those who were most ill or disabled, and there appeared to be a need for extending continued services to these persons in their homes, particularly with regard to nursing services. The hospital staff had been accustomed to refer about 14 per cent of the patients to the Visiting Nurse Association at the time of discharge. It was, therefore, considered logical to extend this practice to meet the apparent needs of more of the discharged patients. The research interest and experience of the staff made it possible to conduct this expansion of services under controlled, experimental conditions which would permit the objective measurement of the effect of these services on the welfare of the patients to whom they were offered.

Members of the Department of Biometry of Case Western Reserve University School of Medicine were actively involved in the study from the beginning. They were challenged by the task of designing a controlled study of a health services program and by its special problems of data handling and analysis. They were responsible for quality control over data and for the appropriateness of inferences drawn on the basis of the study's design.

Another prime motive for the study came from the nursing profession. The faculty of the Frances Payne Bolton School of Nursing recognized that the care of the chronically ill will be an increasingly important part of nursing in the immediate future. They wished to contribute both to nursing education and to better understanding of the sociology of the elderly and chronically ill. In addition to direct collaboration by the nurse-sociologist of the research team, faculty members of the School of Nursing served on the study's steering committee and as advisors and consultants. A major contribution from the nursing profession was the involvement of the Visiting Nurse Association of Cleveland. Staff members of this community agency wanted to know which types of patients in the growing class of the "chronically ill" can profit most by the services of the public health nurse. They expressed the need for more information about the needs of patients after discharge from the hospital and the hope that the study could go beyond the testing of whether or not public health nursing has a measurable effect on the patient's functional level to the correlation of specific aspects of nursing with patient progress.

The study, thus, had its origin in theoretical and practical questions posed by physicians, nurses, and biometricians. The particular medical focus originated in teaching and research experiences with hospital and home care of chronically ill patients.

#### *Acknowledgements*

From the start of the study to its completion almost ten years later, this project was made possible by many people. As a prelude to the book, we wish to express our indebtedness to those who were not in a position to be recognized as authors and to whom so much credit is due. Foremost among them were the three hundred patients who must remain unnamed and who permitted intrusion into a bit of their lives in the hope of contributing to the welfare of others.

Throughout the study, a series of advisors and consultants contributed time and knowledge needed for the project. In the planning stages, Dr. George F. Badger, Professor of Biostatistics, and Dr. Alexander L. Cicchinelli, Assistant Professor of Biostatistics, helped formulate the research design. As the study progressed, Dr.

Badger made available his Department's key punching, electronic computer, and other data processing resources. Dr. Donald Mainland, Professor of Medical Statistics at New York University School of Medicine, also reviewed the experiment design critically. Dr. Harry Posman, Project Director of a related study for the Community Service Society of New York, lent valuable assistance by extending his research experiences during the planning and design stages. Other experts were asked to help establish instruments and procedures in selected areas. Dr. August B. Hollingshead, Professor of Sociology, Yale University, served as advisor in matters relating to the measurement of social class; and Dr. Stephen L. Fink, Associate Professor of Organizational Sciences, Case Institute of Technology, was the project's consultant in psychology. Representing the nursing profession as advisors were Margene O. Faddis, Professor of Nursing, and Dr. Jean L. Stair, Professor of Public Health Nursing, both from the Frances Payne Bolton School of Nursing. Dr. Stair served on the project's steering committee throughout the study, contributing much wisdom and support. Dr. John H. Dingle, Professor of Preventive Medicine at Case Western Reserve University School of Medicine, and Dr. Faye G. Abdellah of the U.S. Public Health Service gave valuable advice during the progress of the study and throughout the stages of manuscript development. Others in the University who encouraged and advised the investigators on a continuing basis were Rozella M. Schlotfeldt, Dean of the Frances Payne Bolton School of Nursing, and Dr. Robert H. Ebert, Professor of Medicine.

Direct interviewing and evaluation was the responsibility of a team of research nurses, physicians, and sociologists, who were rigorously trained to make reliable and accurate observations. Encountering many situations of misfortune among patients, they adapted themselves remarkably well and met the study needs with objectivity and simultaneous concern for humanistic values. This most capable team included: nurses Claire B. Balian, Edna W. Duchon, Sylvia M. Bloomenthal, and Beverly A. Tahari; physicians Reed T. Keller, William B. Newberry, Jr., and Charles L. Schulman; and sociologists Marjorie W. Jaffe and Mildred G. Sindell.

Dedicated to help the chronically ill people in the study was the staff of the Visiting Nurse Association of Cleveland. The agency's full resources were made available, including its staff education program, trained supervisors, and comprehensive services. As the nurse coordinator for the study, Miss Hazel Deuble conscientiously carried out the project tasks within the agency and served as liaison between the investigators and the agency personnel. Appreciation is due to Janet R. Price, Assistant Administrator of the agency, and to all members of the agency's staff, because all were directly or indirectly involved at one time or another. Particular acknowledgment is here expressed to the nurses who served the patients directly, devoting their skills with compassion to the long-term care of these chronically ill people.

In a community study as far-reaching as this, many others contributed time and skills. Though it is not possible to give credit to each and every one by name, sincere appreciation is nonetheless extended to all. Among these were the aides, nurses, physicians, social workers, therapists, administrators, and other staff of Abington House, the hospital where patient selection took place and where professional referral to the study's service program was initiated. Trustees of the Benjamin Rose Institute were responsible for the operation of the hospital, and cooperated fully during the period of the study. The Cleveland Academy of Medicine endorsed the study and encouraged cooperation by local physicians who, without exception,

#### Effects of Continued Care

responded as requested to the service and investigative needs of the study.

Appropriate acknowledgment to the secretarial, programming, and other technical staff of the study is difficult to express. Contributing many woman-years of work with data and manuscripts, theirs was one of the indispensable elements of the project's activities, and is gratefully acknowledged here. Lastly, we acknowledge that this publication is based in part on work performed pursuant to contract HSM 110-69-240 from the National Center for Health Services Research and Development, HSMHA, DHEW; and in part on support in the form of research grants NU-00067, HD-00669, and GM-12302.

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# PART I

*the plan, elements, and results of the study*

## CHAPTER I. INTRODUCTION

The contribution which a nation makes to human history may be judged not only by how it uses economic and political power, but also by how it treats its least favored citizens. The social upheaval following the Second World War has forced the people and the government of the United States to recognize important changes in the social structure of the country. Fortunately, during the past twenty years, an unprecedented economic boom has made possible some advancements for the underprivileged, in spite of two costly wars.

During the same two decades interest has been attracted, less dramatically but no less urgently, to the needs of those who are included in the widening span of social dependency. Three out of every ten Americans are now in school. The problems of youth and education, though still far from solution, have received increased attention which has led, among other things, to our largest and most rapidly growing program of public assistance (1).

In 1965, public attention was directed to the increasing numbers of citizens disabled by age and illness. The passage of the Medicare amendment to the Social Security Act marked a turning point in the history of social legislation in this country. It recognizes formally the obligation of the producing members of society to meet the great needs for health services experienced by those who can no longer earn their own living. The implications of this act for the future are many. Most obvious is the fact that it is bringing about a transfer of medical costs from insurance programs, charities, and private sources to public taxation. The act also incorporates standards of service for nursing homes and hospitals. It opens up new demands

by providing funds for groups of people many of whom had been medically indigent. By linking payment for medical services to the established Social Security system, it sets a pattern for the financing of health services which will almost certainly expand. The final effect of this legislation on the amount, character, and distribution of health services in this country is hard to predict exactly, but it will surely be great (2, 3).

In commenting on a related development in health services, namely, the expansion of hospital services, Titmuss points out that ends tend to be obscured by excessive preoccupation with means (4). The same danger is inherent in a welfare program of the scope of Medicare. The economic purpose of the program is clear. A long public and legislative debate has culminated in general agreement that, since private insurance cannot sustain the cost of caring for the aged and permanently disabled, this economic burden must be shared by all taxpayers. Execution of the program, encumbered as it is with safeguards and compromise provisions, puts new administrative burdens on every segment of a loosely organized health care system. The goal of better health at first seems buried under an avalanche of paperwork, utilization review committees, vendor payment provisions, and confused expressions of demands and needs from the aged and from the professionals who serve them. In the final analysis, the impact of the program on the financing of health services will be difficult to determine, and the effect which it is intended to have on the health and welfare of the people will be even more difficult to measure.

Medicare, thus, raises in a specific area the general question of how health services can be

evaluated. In broad terms, of course, the answer is: by scientific measurement and objective comparisons. The term "health services", however, opens up an extensive field in which medicine, public health, ethics, political economy, and other interests all play a part. Adequate study of even a small element of the health care system requires much time, many skills, a variety of points of view, and careful, critical efforts at quantitation. The investigation which we present in the following pages illustrates the problems encountered in the evaluation of one element of the system, namely, the use of home nursing services to maintain or improve the function of chronically ill, elderly people. In order to represent fairly and objectively as many of the ramifications of such a program as possible, nurses, doctors, sociologists, psychologists, and biostatisticians collaborated in the study. Details of planning, executing, and analyzing a project in which data collection alone took three-and-a-half years were inevitably complex.

The main outlines and findings of the study are presented in Part I of this book. In Part II, we give special consideration to the methods. Before proceeding to the study itself, however, we shall place the problem in its proper context by sketching the main features of chronic illness in the United States today and by summarizing published material about home health services after rehabilitation. We shall complete the chapter by introducing the research questions and approach.

#### *Chronic Disease in American Society*

One in ten Americans is now 65 years old or older. As in other developed countries, this proportion is higher than ever before. The present population structure is the result of high fertility and immigration before 1900, and decreasing death rates since. Special prominence has been given to the current population of aged people by the succeeding lower fertility of the depression years. Current higher birth rates, if continued, will eventually lead to a more evenly graduated population pyramid, but there is no reason to expect the numbers of old people to decrease. For many of the aged, chronic illness

and disability are a way of life, and the prevalence of most chronic illnesses increases rapidly with age. Most people over 65 report that they have one or more "chronic conditions". One-third say that they have limited mobility, and more than half describe themselves as limited in a major activity, such as work or housekeeping (5). A continuation of the current population increase will inevitably lead to large increases in the numbers of people with chronic illness and disability (6).

Mortality figures are often used by those who are concerned with a health problem such as coronary disease to support claims for public attention and for funds. Less striking, but more directly expensive, are the residuals left by the major chronic diseases as, for example, the progressive restrictions of rheumatoid arthritis or the incomplete catastrophe of a stroke. Prevalence of disability is more difficult to measure than death rates. This fact and the relatively low social value which our culture assigns to old people help to explain why their disabilities have been given less attention than the more impressive causes of death among young adults. Among the leading causes of disability, heart disease ranks first as a cause of activity limitation in the United States, according to people interviewed in their homes (5). Arthritis and rheumatism rank second, and impairments of the back and spine third. Among patients in nursing homes, stroke is the most common condition, followed by heart disease and arthritis and rheumatism (7). The mental and behavioral deterioration variously designated chronic brain syndrome, senility, senile dementia, or, euphemistically, "mental and nervous conditions", also ranks high in any survey of disability, although measurement is least precise here.

A particularly knotty semantic problem is that of distinguishing among the overlapping terms, disease, illness, and disability. We use the word "disease" to refer to the presence of any morbid physical or mental state, latent or manifest. "Illness" refers to disease with manifest clinical symptoms, while "disability" means demonstrable loss or limitation of normal function from whatever cause. Thus, for example,

while 16 to 20 per cent of the population in one urban study had some evidence of heart disease by clinical examination, 7 per cent reported that they were ill because of heart disease, while only 1.5 per cent were judged to have moderate or severe disability due to heart disease (8).

The total number of disabled persons in the United States amounts to at least 3.5 per cent of the population, or 7,300,000 people. About 600,000 are in mental hospitals (9), and a similar number are in institutions for the aged and chronically ill (7). Smaller groups of handicapped children are in special schools or institutions. By far the largest group, however, consists of the 6.1 million persons who live at home even though they report some degree of limitation in their ability to move about (5).

The traditional public response to the presence of age and disability in the community has been to establish special institutions such as "homes" for the aged, asylums, nursing homes, and chronic and mental disease hospitals. Two linked social motives, one of removing an inconvenience and the other of providing special care, have influenced the character of every such organization. As long as they have existed, these institutions have had their critics and reformers. Partly as a reaction to the multiplication of institutions in the nineteenth century, criticism of public and private "total" institutions has become more explicit in recent years, emphasizing the dangers of bureaucratic impersonality and the potentially harmful psychological effects of the institution on its members (10, 11, 12). This criticism has contributed to a resistance to the use of institutions, with an inevitable increase in the already large numbers of disabled who live in the community (13).

Few if any communities in the United States are prepared to meet the simplest needs of the existing population of chronically ill persons who live at home. Social organizations which once bore the weight of responsibility for these needs are less able to provide care for the old and disabled. The family unit is pulled apart by occupational mobility, intergenerational conflict, and the costs and pressures of urban living. Churches are beset by financial problems and loss of authority. Voluntary charities are limited

in the support that they command, and their charters may not permit them to cope adequately with modern social needs. At the same time, public expectations of health services are increasing, and the availability of general practitioners to meet expectations and needs is decreasing. Strained by increased numbers of elderly and chronically ill persons discharged from hospitals and other institutions, the existing methods of providing care for the chronically ill and disabled at home show up repeatedly as some of the weakest links in our health care system (14).

In contrast with the development and refinement of in-hospital services in the last two decades, the inventory of services outside the hospital is meager and out of date. This imbalance has arisen partly from a great increase in technological skills and methods, with a corresponding proliferation of specialties which can hardly be practiced outside a modern hospital. In the United States, the trend toward centralized services in the hospital or health center has been accelerated by the rapid growth of health insurance which rarely covers out-of-hospital services. In spite of vigorous efforts at demonstration and innovation, the development of ambulatory clinics, day care centers, home care, and homemaking services has been slow and limited in comparison with those in Scandinavia and Great Britain (15, 16). Increasingly, the patient is expected to come to the medical center for access to scientific medicine and scarce professional time, yet the development of ambulance and transfer services has not kept pace. For the disabled patient confined to his home, modern medicine tends to become more remote and his contact with it more episodic and haphazard. Clearly, he needs help.

#### *Home Health Services After Rehabilitation*

The Commission on Chronic Illness recommended in 1956 that home care be expanded as an alternative to institutionalization of the long-term patient (17). The report also suggested that public health nursing was probably the most commonly used and perhaps the most important element in a successful program of home care. Public health nursing holds a special

place among the health professions in that it directs its services to patients in the community and, particularly, to those at home. The public health nurse is an essential part of home care programs, whether they are based in hospitals or in the community. Home nurses employed by county and state health agencies and by independent visiting nurse associations, in fact, furnish a significant amount of the home health services now available to the American public. The Medicare act, further, recognizes her importance by providing special payment for her services. Despite these facts, inadequate attention has been paid to the nature and effectiveness of these services. We must take stock of our present resources before we can strengthen and add to them; hence, we return to the fundamental question: how effective are the services we are now using?

At the time our project was undertaken, review of the published literature on the aged chronically ill revealed no controlled study of the impact of health services on patients' progress following discharge from a hospital rehabilitation program. Some pertinent reports were, however, available on such related topics as chronic illness, home care, and medical and public health nursing supervision of the chronically ill.

One study, other than ours, was known to be in progress and was also concerned with the role of the public health nurse in the follow-up of chronically ill patients after their discharge from the hospital. This was the study of continued care of impaired older persons by the Community Service Society of New York. It dealt specifically with disabled, older individuals who had received rehabilitation services and had been discharged to the community (18, 19). During the planning stage of the presently reported experiment, it seemed that the two studies would be complementary, since they had related interests and dealt with patients of contrasting social and economic backgrounds.

The Associated Hospital Service of New York, in a study conducted from 1952 to 1957, concluded that at some point in their hospitalization 10 per cent of medical and surgical patients became candidates for home care in-

stead of continued hospital care (20). This evidence of reduced number of days of hospital stay and decreased costs had resulted in the amendment of the New York State Insurance Law to provide coverage for care in the patient's home. Up to 1960, most studies of home care, as the one just cited, had been directed to the economic question of whether home care could be used to reduce hospital costs. Our study, in contrast, was designed to assess the value of home nursing services in maintaining the gains of a hospital rehabilitation program rather than as a means for reducing costs.

A final type of relevant study had to do with continuity of services between general hospitals and public health nursing agencies (21). As one important judgment, the author recommended that a systematic study of continuity of patient care be made in order to determine "the effect of referral and public health nursing services in terms of improvement of patients' conditions and prevention of progress of disease".

#### *The Research Approach and Research Questions*

In analyzing the methods available for assessing medical care provided by physicians, Donabedian identifies three possible approaches (22). The most indirect is the study of the settings and instrumentalities of care, on the questionable assumption that good resources necessarily produce good results. Closer to the point is the second method, the study of the process of care, with judgments based on defined values and standards. Using this method, description may be accurate, but a large subjective element of judgment cannot be avoided. Judgments often vary, and such a study tends to reveal more about the raters than about the service being rated. The most direct method of assessing medical care is to use objective measures of outcome as the criteria of quality. Preciseness and objectivity permit more reliable inferences; therefore, the decision was made to use outcome criteria in the present study. As Donabedian also points out, the kind of outcome must be specified; and he lists three kinds, namely, recovery, restoration of function, and survival. Recovery cannot be used in the study of chronic diseases which are incurable. In the present

study, restoration or maintenance of function and survival were assessed; and an additional aspect of outcome was examined, namely, use of services.

Another problem to consider in the use of outcome criteria is that of the relevance of the measures to the services under study. Can periodic home visits by a nurse, for example, reasonably be expected to alter survival? Maintenance of function appears to be a more relevant criterion of nursing service. Is increased use of services to be interpreted as costly excess, necessary therapy, or preventive medicine? Such questions can become quite involved and their interpretation correspondingly uncertain.

Home care of the chronically ill takes place "in the field", as the epidemiologist would say, and it is at least as much a social process as a medical one. Epidemiological and sociological methods must, therefore, be combined with clinical observation; and because of this complexity, most studies of health services tend to be limited to description. Case studies are sometimes used to evaluate services and to offer a framework, although a shaky one, for comparisons and decisions about services. Rarely does the opportunity arise to evaluate a program of health services by establishing a control group according to strict methods of random assignment. The present study was designed to take advantage of one such opportunity.

As described in the Preface, a favorable set of local circumstances made the study possible. We were physicians, nurses, and biostatisticians who had long-standing professional experience with chronic illness; and we were engaged in teaching, in research, and in hospital and home care. Having practical and theoretic interests in common, we collaborated to plan and to conduct an experimental, controlled study of the outcome of a sustained program of home nursing services for patients discharged from a chronic disease rehabilitation hospital. The outcome would be defined by measured changes in the well-being of experimental and control patients.

We agreed that it would be desirable to hypothesize detailed relationships between specific elements of home nursing care and relevant measures of outcome. A nurse's supervision of

prescribed exercises, for example, might result in improved physical mobility; but many other factors would also influence mobility over a period of time. Some factors would be indirectly related to the nurse's activity, such as general health and morale, and some would be largely unrelated, such as the natural progression of the disease process or the presence of physical obstacles such as stairs. Because of the multiplicity and complexity of relationships between the experimental variable and measures of outcome, we decided to state a single, general hypothesis and then to examine it from as many different specific viewpoints as possible. The hypothesis was that:

after discharge from a chronic disease rehabilitation hospital, patients whose care is regularly supervised in the home by a public health nurse (working with the patient's physician) will more often maintain or increase physical, psychological, or social function than will patients whose care is not so supervised.

A second hypothesis was implicit in the planning of the study. This hypothesis was based on the concept that home care by public health nurses is one link in a chain of health and welfare services (23). Viewed in this way, one of the important effects of the nurse's services is to facilitate the patient's access to other health services and to increase their use for appropriate purposes. This is not a new idea, but it assumes new importance as the complexity of health services increases. Public health nurses have, for decades, been urging patients to see their doctors and to keep clinic appointments. Like other members of the health service team, the public health nurse functions as an essential "enabler" (24). Our concern with this aspect of public health nursing was evidenced by the fact that the research protocol included questions about the use of hospitals and nursing homes, and included counts of the services of doctors, nurses, and other health professionals. The second general hypothesis of the study was, therefore, that:

after discharge from a chronic disease rehabilitation hospital, patients whose care is regularly supervised in the home by a public health nurse (working with the patient's physician) will make more use of other health services than will patients whose care is not so supervised.

The testing of these two hypotheses was the immediate objective of the research. In undertaking this complex and time-consuming study, however, we intended it to have practical as well as theoretical value. Although we examined only a part of the health services system, it is a part of the system about which little is known, in spite of a pressing need for development. The description of outcome in relation to services given to a large group of chronically ill patients could, in itself, provide useful guidance for practitioners and teachers of public health nursing, as well as for physicians who are responsible for the care of the chronically ill at home. The scope and duration of the study would offer opportunities to develop and test methods of measurement and longitudinal data analysis. Above all, specific knowledge about predictable results of home care would add to the basis of fact on which rational planning must rest. Finally, we hoped that a study focused on the welfare of the patient would draw attention to a neglected aspect of health services, with resulting benefit to those who are disabled by age and chronic illness.

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## CHAPTER II. THE RESEARCH PLAN

Careful planning of the research was essential to avoid predictable sources of bias. An understanding of the study and its results requires thorough description of the plan and process, as well as detailed definitions of terms. Needed, also, are descriptions of the two kinds of health service programs which are identified in our hypotheses, namely, the programs of the chronic disease rehabilitation hospital and of the voluntary community agency which provided home nursing services. We describe the research plan and its implementation in this chapter. In the next three chapters, we present information about the patient sample, the service programs, and the study measures.

Practical problems often set stringent limits on how one can study a program of health services by experimental methods. For example, potential subjects and service personnel may object to the randomized giving and withholding of service if it seems to them unnecessary or unfair. A second type of limitation is the difficulty of accumulating complete and reproducible information in long-term prospective studies, a limitation which is particularly evident in the field of chronic illness where patients may be lost through death or other causes and where the research program is difficult to sustain. A third problem is that of finding measures which are both reliable and valid and which can serve as relevant criteria of the outcome of treatment. On the other hand, nonexperimental studies are always open to the criticism that the cause and effect relationships between the health services and the study results are rarely clear.

The circumstances of the present study permitted us to overcome certain of these limitations and to plan a prospective, controlled, experimental study based on random assignment of treatment. Favorable elements were: (1) two of us, as directors of the hospital and the public

health nursing service involved, could regulate important aspects of the service program, and (2) our research team was experienced in observing the progress of patients with chronic illness.

We defined the "treatment" to be studied as the program of care which resulted when a public health nurse was assigned to assist in the care of a patient discharged from a hospital for the chronically ill. This one variable was to be controlled (i.e., provided for or withheld from study subjects) as carefully as possible. Other variables which might affect the outcome, such as age, diagnosis, and functional state, were considered to be too numerous to serve as a basis for stratified sampling. Certain variables, in fact, which might affect the outcome could not be identified. We, thus, chose a system of random assignment as the method of allocating patients to the experimental groups, with a sample size large enough (300 patients) to allow comparable distribution of extraneous variables in each experimental group.

### *Research Design*

The basic plan of the study was that 300 patients were randomly assigned to treatment or control groups at the time of discharge from the hospital, the treatment consisting of regular visits by a public health nurse to the patient at home. Each patient was observed during a period of two years after discharge by a separate team of observers trained to apply specific measures of physical, psychological and social function. We separated observers from care personnel in order to avoid the bias of those who gave service. In addition, we regulated the frequency of research observation. Patients were randomly assigned either to a group observed at quarterly intervals or to a group observed only at the beginning and end of the study, in order to permit detection of effects related to the process of observation.

We designed the sample size as large as available resources and time would permit, so that subgroups within the somewhat heterogeneous total groups could be examined. We chose the observation period of two years because the illnesses which originally led to admission to this particular hospital were largely chronic and usually necessitated a long-term nursing plan. Previous studies had shown that, although measurable improvement in function occurred most frequently during the first year after discharge, some patients improved between the first and second years (1, 2). Observations were not extended beyond two years because two-year mortalities of the order of 40 per cent had been observed in patients with stroke and hip fracture discharged from this hospital. This experience suggested that the sample could become too small to be useful after two years. Three months was selected as the interval between observations. We estimated this to be a period long enough to permit the available staff to visit the assigned patients in their homes and yet short enough to observe and recall changes in functional status.

A well-recognized principle of behavioral research is that the process of observation influences the behavior itself (3). Since we planned to observe the subjects at intervals for two years, we could predict that a relationship would develop between the observer and the patient. Such contacts, which would in certain ways resemble the interaction between the public health nurse and her patient, might affect the patient's behavior and obscure differences between treated and control groups. For example, a patient repeatedly questioned about when he last saw the doctor and about his functional limitations might be prompted to make more frequent appointments with his doctor, and might change his approach to his physical limitations, whether the questions were asked by a neutral observer for research purposes or by a public health nurse undertaking a plan of care.

We adopted, therefore, the sample design presented in Table 2.1 in order to permit identification of changes related to the nursing program, changes related to regularly scheduled observation, and changes related to interactions

Table 2.1—Basic Design of Sample\*

	Referred to Visiting Nurse (N+)	Not referred to Visiting Nurse (N-)	Totals
Observation classes			
Observed every three months (O+)	75 (N+O+)	75 (N-O+)	150
Observed only at intake and termination (O-)	75 (N+O-)	75 (N-O-)	150
Totals	150	150	300

\*Figures are numbers of subjects.

between the nursing program and observation process. The design is called a *factorial design*, and methods for analyzing and interpreting results based on such designs are well known (4, 5).

We established four equal-sized groups which differed systematically both in the treatment assigned and in the frequency of observation. By this means, we distinguished several types of effects. Effects on patients who were assigned to the nursing program were identified by comparing the 150 patients who were "Referred to Visiting Nurse" (Table 2.1) with the 150 who were "Not Referred to Visiting Nurse". In this comparison, effects of the observation process alone were eliminated since the presence or absence of systematically repeated observation was balanced equally between the groups assigned and not assigned to the nursing program.

Effects related to systematically repeated contacts with an observer were recognized by comparing the 150 patients who were "Observed every three months" (Table 2.1) with the 150 who were "Observed only at intake and termination". In this comparison, effects of the nursing program alone were eliminated since the presence or absence of the nursing program was

balanced equally between the groups assigned to systematically repeated observation.

Effects on patients who were assigned to the nursing program (comparison of the 150 who were "Referred" with the 150 who were "Not Referred") were not, in all instances, attributable solely to the nursing programs, since interaction between the nursing program and the observation process was a potential source of bias in one-fourth of the sample and was not balanced in the study design. We could, however, measure and sort out the interaction bias. Differences related to interactions between the nursing program and observation process were identified by comparing combined groups in which the nursing program and systematically repeated observation were present separately (N+O- and N-O+ groups in Table 2.1) with combined groups in which the nursing program and systematically repeated observations were both present and both absent (N+O+ and N-O- groups in Table 2.1).

In some instances, e.g., analyses of quarterly interval findings, it was necessary to examine nursing effects by comparisons between the 75 systematically observed patients who were "Referred to Visiting Nurse" and the 75 systematically observed patients who were "Not Referred to Visiting Nurse". In such instances, the observation process was a potential source of bias for interpretations about nursing effects. Unless otherwise stated, *nursing program effects reported in the book are effects that were neither observer-biased nor interaction-biased.*

#### *Study Intake*

According to the research plan, we admitted 308 patients into the study at the time of discharge from Abington House (formerly the Benjamin Rose Hospital). The 308 were those consecutive patients who met the following criteria: (1) discharge to a home (noninstitutional residence), (2) residence within the area served by the Visiting Nurse Association, (3) age 50 years old or older, (4) hospital stay of at least one week, and (5) did not leave the hospital against advice. The first eight patients were designated as a pilot group. The purpose of the pilot group was to provide an opportunity at each stage of the

study for practice and adjustment of procedures. Data related to these patients were not to be included in the analyses. Like the other patients, they passed through the complete 2-year study process. None of the observers or nurses was informed of the special status of this group.

Random assignment of patients to observer and treatment groups took place in two stages. The biostatistician prepared a set of 308 sealed envelopes, each envelope containing an observer assignment and, in an inner sealed envelope, an assignment to one of the four experimental groups (Table 2.1). A member of our research staff kept a log of all patients in the hospital and recorded the estimated dates of discharge at regularly scheduled intervals. When a patient met the intake criteria and when his discharge was estimated to be seven days away, we assigned him a study number and opened the first envelope to determine to which observer he was assigned. In order to ensure that knowledge of a patient's experimental group did not influence the observer's initial evaluation or the hospital discharge plan, we withheld opening the second envelope which contained the experimental group assignment until an estimated three days before discharge. We considered three days to be the minimum required to make an orderly referral of the patient to the Visiting Nurse Association. The date on which the patient was assigned to an experimental group was designated the intake date. Time intervals reported later are measured from this date, unless otherwise specified. Terminal evaluations of all surviving patients were scheduled on the second anniversary of the intake date.

The randomization procedure was designed to ensure that, at the time of intake, each patient had an equal chance of being assigned to any one of the four experimental groups. Since we expected the intake process to last more than a year (actually lasted 22 months), the scheme of randomization was divided into blocks of twenty successive patients, starting with case number 9, after the pilot group. Within each block, each experimental group included five patients. By this means, variations related to time, such as seasonal effects or changes in service staff and program, were evenly distributed; and

convenient termination points were provided. We did not inform observers about the details of the random process.

As soon as a patient was assigned to an observer (at the time of opening of the first envelope), the observer introduced herself to the patient and conducted the intake interview. One of the physician investigators supplemented this interview with additional interview, physical examination, and laboratory data. We explained the study as an effort to learn more about patients and their progress in order to improve patient care.

When the patient was assigned to an experimental group (at the time of opening of the second envelope), nothing further was done in relation to those who were to be control patients (not referred to visiting nurse) except that the observers made arrangements to see those who were to be observed regularly. When a patient was assigned to a treatment group (referred to visiting nurse), one of the physician investigators immediately approached the physician who would be caring for the patient after discharge and asked his permission to refer the patient to the Visiting Nurse Association. No physicians refused this permission. The investigator then initiated the referral, explaining to the patient and his family that this was recommended by the hospital staff as a means of maintaining progress achieved in the hospital.

In regard to fees, the usual agency policy was followed. Each nurse thus evaluated the needs and resources of each patient during the first few visits and set a fee, ranging from full cost (\$6.25 a visit) to no charge. At the time of referral to the Visiting Nurse Association, the members of the hospital staff who had been caring for the patient completed a standard form, the Greater Cleveland Confidential Referral Form, which presented details of diagnosis, medications, orders for treatment, and summaries of nursing, social work, physical and occupational therapy experience. This form was sent to the Visiting Nurse Association.

The care offered to the patients in the treatment group was basically that regularly provided by the Cleveland Visiting Nurse Association. We describe nurse selection and neces-

sary modifications in the patterns of service in Chapter 4. Although it would have been desirable to randomize the assignment of nurses, this was not practicable.

We carried out the intake process as planned. In the final analysis, there were 75 patients in each of the four experimental groups. Of the 300 subjects, all but six had their initial evaluations by the assigned observer. These six were seen by substitute observers.

### *Interval Observations*

Previous studies of patients discharged from Abington House had shown that important changes in such functions as walking and activities of daily living frequently occurred immediately after discharge and less frequently later. For this reason it seemed advisable to plan to see the patient soon after his return home. A second reason for planning an early visit had to do with methods. Previous experience with the Index of Independence in Activities of Daily Living had brought out the fact that, in addition to valid changes in function associated with the move from hospital to home, artifacts might be present in either setting. The design and location of closets and bathrooms, for example, might influence the degree of independence in dressing and using the toilet. Early observations in the home were, thus, desirable for us to identify the number of such artifacts and to establish a baseline in the home as well as hospital.

The first set of observations for the 150 patients who were to be visited every three months was, therefore, scheduled for one week after discharge. The date of this post-discharge visit is the only one which we did not base directly on the study intake date. Instead, because of the logical relationship of this visit to the actual discharge, we based it on the discharge date. When all the subjects had been taken into the study, we found that the actual mean interval from intake date to discharge was  $5.4 \pm 7.3$  days,<sup>1</sup> where three days had been

<sup>1</sup>The notation  $5.4 \pm 7.3$  days indicates that the average time between intake date and hospital discharge was 5.4 days, while the standard deviation was 7.3 days. The distribution of times here is highly skewed, as evidenced by the fact that the standard deviation is greater than the mean.

planned. The post-discharge visit, on the average, took place  $7.2 \pm 7.1$  days after discharge from the hospital.

For the half of the subjects who were to be observed quarterly, we scheduled visits (after the one week post-discharge visit) every three calendar months from the intake date. Visits were continued by the same interviewer who had conducted the intake interview until the end of the planned two-year period of observation or as long as the patient lived. Observers travelled to the patient's home or other residence. The subjects, as we anticipated, proved to be a geographically stable group. Only nine moved out of the community. Of these, seven were close enough to be visited in person. One moved to Texas and one to Florida. Information about these two was obtained by telephone from the subjects and their personal physicians.

One-half of the subjects, by design, were not to be interviewed by observers between intake and the terminal date two years later. One-half of these were to receive nursing visits, leaving one-quarter of all the subjects with whom no contact would take place during the two years. In order to keep track of this one-quarter, one of our research staff made a telephone call every six months to the last known address in order to determine if the subject was still at the same address. The regular observers were not informed of this contact.

#### *Deaths*

Information that a regularly observed patient had died was obtained by the observer when she attempted to arrange the next quarterly interview, and sometimes sooner through obituary notices or other channels. In the group observed only at intake and termination, death was ascertained from the nurses or by routine semiannual telephone checks and, for all patients, at the terminal date.

#### *Terminal Observations*

The terminal observations were among the most critical of the study, since it was at this point that we were to make comparisons among the four original experimental groups. A primary consideration was to approach both the ob-

served and so-called nonobserved groups in the same way. For this purpose, the original observer was not appropriate, since she had come to know half of her subjects quite well over a two-year span, while she had not seen the other half since intake. We decided, therefore, to assign an unfamiliar observer to every subject for the terminal interview by a random method and to have the new observer approach every patient without consulting the regular observer. The information collected by the new observer is that which has been used for all group comparisons unless stated otherwise. Two physicians repeated certain evaluations as well. Because of staff changes, we could not reassign physicians systematically, but this was not considered to be essential since they had not seen any of the patients for the intervening two years.

A second set of terminal interviews was conducted following the basic ones defined above. These involved only the quarterly observed subjects and were conducted by the originally and regularly scheduled observers. Duplicate terminal data were thus obtained which permitted us to compare information obtained by an observer who knew the subject well with that obtained by one who had not known the subject previously.

#### *Organization of the Staff*

A study which lasts four years and deals with 300 subjects distributed throughout a major metropolitan area requires a large and well organized staff. In addition to the nurses who gave the care, sixteen professional persons, three secretaries, two programmers, and a keypunch operator spent major amounts of time on the study. We established a steering committee consisting of the principal investigator, the project director, the biometrician, the directors of observer and care teams, and a public health nursing consultant. This group remained the directing committee from the initial planning phase through the completion of this book and was assisted by a psychology consultant.

In an experimental study of health services, the strict "double blind" technique which is used in studies of drug effects is frequently not possible. The purpose of this technique is to

prevent the observers who measure the criteria from being influenced in their judgments by knowing which subjects are receiving the experimental treatment and which are the control subjects. This method is "double blind" since both subject and observer are prevented from knowing who belongs in which group. It is obviously impossible to supply home nursing care to one group while withholding it from another and to conceal this difference completely from subjects and observers. Nevertheless, steps can be taken to minimize the bias from this source.

In specific ways, we designed the program to prevent observers from being affected by knowledge of who was receiving what service. Prior to starting intake, the observers were instructed in the methods of the study. Their headquarters were remote from the nursing service, and their only contact with the care team was through their director (Dr. Mary Adams) who sat on the steering committee. We did not tell the observers which patients were receiving nursing service, and we gave them only general information about the goals and methods of the nursing program. We instructed them not to offer any kind of service and to refer questions about service to the team director. She, in turn, communicated such questions to the nurses only in the rare instances when there seemed to be no other way to meet a critical need.

The care team consisted of the Visiting Nurse Association staff, augmented by a nurse coordinator employed for the study. The director of the agency served as director of the care team. The nurses were asked to keep special records and to keep treatment cases open for two years. We did not give information to agency staff about which patients were under regular observation, nor about the kinds of observations which were being made. Criteria of observer judgment were not explained to the nurses. We referred all questions which arose about the overall study or the observers' visits to the director of the care team and, thus, indirectly back to the observer team. In chapter 4, we present information more fully about the nursing program.

In the lives of many of the people who were

being studied, the visit of the nurse or the observer was an important event. Subjects occasionally told members of one team about the activities of the other. Observers also discovered that some discharged patients maintained regular contact with friends they had made in the hospital, even though they lived in different parts of the city. There was, therefore, a small amount of inevitable communication between experimental groups. Communications between those providing the care and those evaluating the results were, by design, made sufficiently difficult that no major communication of this latter type was possible.

#### *Data Collection*

"Physical, psychological, and social function" are the criteria by which we evaluated experimentally the outcome of the home nursing program. Many of these functions involve ordinary activities or behavioral responses to a test stimulus. The standardization and measurement of such responses is beset by many limitations. The conditions of observation are variable, and certain data consist of partially judgmental reports of human behavior. In view of this, we used precise and objective measurements when they were available, as in the definition of disease states in terms of laboratory findings:

Some of the measures which are most relevant to our hypotheses, however, depend for their validity upon skillful interviewing or trained personal observation. The preparation and training of the observers and the methods they used to elicit information was, therefore, an important determinant of the quality of the data. The following general principles are developed in greater detail in Chapter 5.

The individuals who collected the data had training in a variety of professional fields. Three were physicians. One of the two full-time observers was a registered nurse, and one had a master's degree in sociology. Part-time observers and substitutes were also nurses and sociologists. We assembled the research staff and instructed them in the measures to be used and in interviewing methods before intake began. Three observers had had previous experience with similar studies in the same setting. Throughout

the study, the observers met daily with the director of the observer team and at intervals with the principal investigator and project director to report their experiences, to clarify definitions, and to obtain guidance in difficult cases.

Concerted efforts were made to obtain as complete and accurate information as possible. We considered the primary source of information to be the patient. When aphasia, language barrier, or confusion made this information questionable, or in the rare instance when the patient could not be visited personally, we turned to secondary sources, such as the patient's family or his personal physician, and occasionally to friends, practical nurses, landladies, nursing home staff, and others. When information seemed doubtful to the observer because of inconsistency or confusion on the part of the informant, checks were made with other informants. For certain data, such as dates of birth and hospitalization, the observers routinely checked information obtained from the subject against public and institutional records.

We wanted the approach to the patients to be reassuring and to gain their cooperation over a two-year period. Interviewers arranged their interviews according to the patient's tolerance and wishes. In order to avoid the use of clipboards and forms, observers memorized the data schedules and completed them promptly after leaving the patient. Observers explained the purpose and nature of the study in general terms as an effort to "learn more about you and how you progress so that we can do a better job of caring for people with similar difficulties in the future." The experimental character of the study and its official relationship to the hospital were explained appropriately.

We set limits to the intimacy and professional content of the interviews. Observers were instructed to present themselves only as friendly inquirers and not to give advice about professional or personal matters. With few exceptions, the effort to preserve an interested but impartial approach was successful.

Records were kept on the forms which are presented in Chapter 13. Once an interview was recorded, changes could be made only through the director of the observer team, who was also

responsible for reviewing all the data and assuring its completeness.

From the original data sheets, two coders coded information independently. Each set was keypunched separately on IBM cards. The cards were then compared electronically; and the director of the observer team reconciled all discrepancies, working with other members of the staff on definitions and interpretations. The reconciled cards were repunched and compared again, and the process repeated until there was complete agreement between the two sets of cards.

The nurses who were assigned to patients in the study kept separate records. From these records, data summarizing the dates and content of each visit were abstracted on mark-sense sheets, punched on cards, and verified.

We collected some kinds of data in duplicate in order to permit a formal check of reproducibility. For example, two different observers interviewed the survivors of the quarterly observed groups after two years. There are limitations, however, to the meaning of reproducibility measured in this way. Many of the data are time-dependent, and it is impossible to conduct simultaneous interviews. The mental and physical state of the patient during the interview, its location and timing, and many other variables may influence a measurement or evaluation result and cannot be standardized in a study such as this one.

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### CHAPTER III. THE PATIENT SAMPLE

During the present century, radical changes have been taking place in the population age structures of the developed countries and in the major health problems with which the health service systems of these countries are confronted. In the United States, persons aged 65 and over are now approaching an unprecedented 10 per cent of the population. The leading causes of death and disability have shifted from the acute infectious diseases, with their impact on the first segment of the life-span, to the chronic degenerative diseases, which increase steadily after early adulthood.

In our daily work as physicians, nurses, and directors of services, we have had thrust upon our attention the problems generated by the chronic illnesses and disabilities of older people. It is clear to the most casual observer that existing health services in this country cope with the health problems of such persons in a discontinuous and fragmented manner. We designed the present study, therefore, to find out whether the planned use of one available method of coordinating and continuing health services — namely, a program of continuing visits by a public health nurse, supervised by a physician — could be shown to improve or maintain the function of a group of such persons.

Men and women 50 years old and older, who were about to be discharged home after being hospitalized for a chronic illness or disability, were chosen as the subjects of this study. In general terms, these patients and their problems are typical of those being seen in steadily increasing numbers in hospitals, rehabilitation services, public health nursing agencies, and at other points of contact with the health care systems in the United States today.

We chose this particular sample because of a common opinion that such patients need more

and better coordinated care than they usually receive (1, 2). In addition, these individuals happened to be passing through one channel of the health care system over which we could exert enough control to introduce or withhold a particular element of health service, namely the home visits of a public health nurse.

There were additional reasons leading to the choice of this sample. For one thing, on the basis of previous studies, we already knew a good deal about the patients in this particular hospital and could make some predictions about them, such as that they would sustain a 20 to 40 per cent mortality over a two year period after leaving the hospital. We had also developed measures in the earlier studies which would be useful for describing these patients. Motivation for the study came from the need to know more about alternative ways of providing care for such chronically ill patients, since information about methods of caring for this growing population could be used to improve the service programs of the hospital and the public health nursing agency and could increase the fund of knowledge for medical and nursing students.

#### *The Hospital*

The hospital, Abington House, from which the sample was obtained is a unique institution. In many ways it resembles what Phillips has called the "intermediate" hospital—intermediate, that is, between short-term general hospital care and home or long-term institutional care (3). Abington House (formerly the Benjamin Rose Hospital) was built by the Benjamin Rose Institute in 1954. The Institute had been endowed in 1908 by Benjamin Rose, a Cleveland philanthropist, "to provide help and sustenance to needy older persons." The hospital is a unit of University Hospitals of Cleveland and is staffed by

faculty members of Case Western Reserve University School of Medicine.

The hospital, located on the border between the inner city and its suburbs, has provided hospital and rehabilitation services for patients referred by physicians about equally from University Hospitals and from elsewhere in the Cleveland area. There are 66 beds. The patients admitted to the service are similar in many respects to those admitted to four chronic diseases hospitals or units described by Goldman (4). Typically, patients at Abington House need restoration of physical function after sustaining, for example, a hip fracture or a stroke. Many patients, also, need comprehensive evaluation and planning as, for example, an elderly person who has encountered difficulty in managing on his own. In addition to medical and nursing services and the consultation and laboratory facilities of a large university hospital, special services are emphasized, including medical social work and physical, occupational, and speech therapy. Planning for care after discharge is stressed, with most patients returning to the care of private physicians. The patients are mainly, though not exclusively, elderly. The average stay is a little over a month, and two-thirds of the patients are discharged to their homes in the community.

#### *Sample Selection*

Three hundred and eight subjects were selected from 831 consecutive patients discharged between July 15, 1963 and May 5, 1965. The criteria we used for selection were: (1) discharge to a home (noninstitutional residence), (2) residence within the area served by the Visiting Nurse Association, (3) age 50 years old or older, (4) hospital stay of at least a week, and (5) did not leave Abington House against medical advice. We applied these criteria to all patients in sequence as they approached discharge, and every patient who met the criteria was taken into the study.

The largest number of patients excluded from the study were excluded because they were not eligible to receive the services of the Visiting Nurse Association. This agency, by agreement with local governmental agencies, provided

home nursing services in the central metropolitan area and much of the suburbs, while the remaining areas were served by local public health authorities. This agency provided nursing services only in homes, apartments or boarding houses, and not in hospitals, nursing homes, or homes for the aged. Elimination of 227 patients who did not return home and 143 who lived outside the Visiting Nurse Association area accounted for almost three quarters of the exclusions.

The study design called for the elimination of certain small groups of patients who were atypical of the population under study and not numerous enough to comprise a sub-sample. These were: those under 50 years of age (38 patients), nonwhites (10 patients), and individuals who left the hospital against medical advice (4 patients). Finally, 101 patients who did not meet other criteria for eligibility were excluded prior to randomization. Included among the 101 were 38 patients who died in the hospital, 23 who were already in the study because of an earlier admission, 24 who were hospitalized less than 6 days, and 16 who were discharged earlier than the patient with the final study number (whose discharge was delayed).

The first eight patients, as noted in Chapter 2, were the pilot group. One substitution was drawn from this group and included in the final analysis. This occurred when patient number 16 left the hospital against medical advice, and patient number 5 (who had the same random treatment and observer assignments) was substituted. We made no other alteration in the composition of the sample after study numbers had been assigned. The sample which was finally analyzed, thus, consisted of the planned 300 patients, or 36 per cent of the patients discharged in 22 months.

The remainder of this section will be devoted to a description of the physical, psychological, and social characteristics of the 300 subjects at the time of their entry into the study. We shall, also, make comparisons with data from other studies to give an idea of the representativeness of the present sample.

### *Age*

The mean age of the patients in the present study at the time of intake was 72 years, with a range of 50 to 94 years. The age distribution, except for the purposeful exclusion of those under the age of 50, is similar to that reported for the patients in four other chronic disease hospitals (4). Three-fourths of the study patients were 65 years old or older, and persons in this age range generally constitute about a third of the case load of home nursing services. A national survey in 1963, for example, found that 36 per cent of the patients receiving home nursing from 219 public health agencies across the country were 65 and older (1).

The Visiting Nurse Association of Cleveland reported 32 per cent of their patients to be older than 65 in 1966, while the Associated Hospital Service of New York gave home care to 5000 individuals, of whom 42 per cent were 65 or older (2, 5). These figures may underestimate the problem, since a national sample of household interviews in 1958-9 showed 6.6 persons per 1000 in the U. S. population to be receiving personal help or nursing care at home, of whom 58 per cent were 65 or older (6). Since the Medicare law went into effect in July, 1966, the proportion of older people referred for home care has been increasing.

### *Sex*

There were 99 men and 201 women in the sample. This a ratio of 49.3 men to 100 women, which is a much greater preponderance of women than is found among people in the United States who are 65 and older. In 1965, the ratio of men to women for this part of the population was estimated to be 77.6 to 100 (7). Among patients over 65 who were receiving home care, a household survey also revealed a higher ratio of men to women than did the present study, namely 64.5 to 100 (6).

### *Disease*

The classification of persons on the basis of disease offers formidable problems and is discussed further in Chapter 6. For the purposes of the present study, we used two bases for disease classification. First, we assigned to each patient

a single principal clinical diagnosis or "diagnosis leading to hospital admission". This is a classification based on illness, or manifest disease requiring hospital services. In order to arrive at this diagnosis, two of the physician investigators read every patient's entire chart and resolved any questionable decisions jointly. This process resulted in the list of diagnoses presented in Table 3.1. When these diagnoses are compared with the distribution of diagnoses in studies of similar populations, it appears that our sample includes more patients with stroke, fracture of the femur, and arthritis, and fewer with heart disease and cancer than are generally encountered by public health nurses giving home care to elderly patients (1, 2). This distribution clearly results from the fact that the patients selected were those discharged from a hospital which offers physical rehabilitation as one of its primary services. The kinds of disease seen in this study resemble more closely those reported in a related study which also drew its sample from a rehabilitation-oriented hospital (8).

The leading causes of death in the United States among persons older than 50 years of age are, in order of magnitude, diseases of the circulatory system, neoplasms, diseases of the nervous system, and accidental injuries (9). These conditions are numerically well represented in this study. The two conditions reported by the National Health Survey to account for approximately 40 per cent of the chronic limitations found in persons 45 and older are heart conditions and arthritis and rheumatism (10). These are also represented among the larger categories in our present study.

We established a second classification, based on systematic screening of all patients at intake for the presence or absence of twelve commonly occurring chronic disease abnormalities (Table 3.2). Additional information about the definitions for the study of these particular conditions is presented in Chapters 5, 6, and 13. The list is not exhaustive, but it does document the great prevalence of chronic disease in this patient population. Only one in seven patients was free of all the twelve conditions which were considered. More than 60 per cent had two or more conditions, and four patients had six. The results

Table 3.1. Diagnoses Leading to Hospital Admission for Study Sample

ICD Code <sup>1</sup>	Disease classification	No. of persons	Per cent of total
330-398	Nervous System and Sense Organs		
	Stroke	77	34.7
	Paralysis agitans	6	
	Other	21	
	104		
800-999	Injuries—External Causes		
	Fracture of femur	59	23.7
	Other fracture of lower limb	12	
	71		
720-749	Bones and Organs of Movement		
	Rheumatoid arthritis	16	14.3
	Osteoarthritis	10	
	Other	17	
	43		
400-468	Circulatory System		
	Arteriosclerotic heart disease	15	9.0
	Vascular disease with amputation	6	
	Other	6	
	27		
300-329	Mental, Psychoneurotic and Personality		
	Chronic brain syndrome	20	7.3
	Depression	2	
	22		
140-239	Neoplasms	13	4.3
530-587	Digestive System	13	4.3
240-289	Allergic, Endocrine, Metabolic and Nutritional	3	1.0
470-527	Respiratory System	1	0.3
290-299	Blood and Blood-forming Organs	2	0.7
590-637	Genito-urinary System	1	0.3
	<b>TOTALS</b>	<b>300</b>	<b>99.9</b>

<sup>1</sup>ICD Code is taken from the International Classification of Diseases, Adapted, published by the U.S. Government Printing Office, Washington, D.C., 1962.

of this screening, compared to the diagnoses for which patients were hospitalized, reveal more clearly the sources of disabilities which may be expected to influence the outcome of any treatment program. Cardiovascular-renal disease, for example, was definitely or probably present in about three-fourths of the patients, although

less than 10 per cent were admitted for this reason. Although no patient was admitted to the hospital because of blindness and only one because of obesity, each of these conditions complicated efforts to restore independence to approximately one out of every ten patients. Conditions which usually imply a poor

Table 3.2—Chronic Disease Abnormalities

Abnormalities	No. of persons
Cardiovascular-renal System	
Arteriosclerotic heart disease	125
Vascular heart disease	65
Hypertension	63
Other cardiac abnormalities (digitalis or EKG abnormalities of fibrillation, T-wave changes, or block)	111
Protemuria	37
Azotemia	20
Metabolic and Nutritional Conditions	
Diabetes	44
Obesity	25
Sense Organs	
Blindness	36
Locomotor System	
Noninflammatory polyarthritis, past month	33
Inflammatory polyarthritis, past month	18
Neoplasms	
Malignancy present in past five years	26
Combinations of Above Abnormalities	
None of the abnormalities	42 (14.0%)
One abnormality	75 (25.0%)
Two abnormalities	87 (29.0%)
Three abnormalities	56 (18.7%)
Four or more abnormalities	40 (13.3%)

prognosis, such as arteriosclerotic heart disease, malignancy, and chronic renal failure were shown to afflict many patients, even though these were often not the admitting diagnoses. Such conditions limit rehabilitation goals and must be considered in interpreting the results of a program of care.

#### *Physical Disability*

Disability is a term which refers to loss of capacity to perform a function. This definition

of disability is similar to that used in the National Health Survey: "Any temporary or long-term reduction of a person's activity as a result of an acute or chronic condition" (6). Objectively, disability can only be identified when an individual is required, by request or by circumstances, to perform a function and fails to do so. An investigator in a study such as ours cannot determine whether there is latent capacity which would result in performance if motivation or other circumstances were different. The measurements of disability presented in Table 3.3, therefore, are reports of actual performance.

The subjects had many and severe disabilities at the time of intake into the study. Only 17 persons needed no assistance with their activities of daily living. A little more than half had full use of all four limbs, and only 40 were able to walk without personal assistance or mechanical support such as a cane. One-third had been unable to go outside their places of residence during the two weeks before being admitted to the hospital. On the other hand, few were totally disabled. Only four were completely bedridden, and all but 50 were walking in some fashion.

Patients with strokes composed the largest diagnostic group, but other conditions such as arthritis and multiple sclerosis also produced limitation of movement in the limbs. As noted in Table 3.3, we found that 31 per cent of the 300 patients were severely restricted in strength and range of movement, meaning major limitation in the function of at least one limb (rating of U3 for an arm or L3 or L4 for a leg as defined in Chapter 13). The most common pattern was moderate or severe limitation in one limb (53 patients). Hemiplegia or hemiparesis was identified in 49 patients, weakness of both legs in 5, of both arms in 10, of three limbs in 7, and of four limbs in 11. One patient had limitation of an arm and a leg on opposite sides.

In summary, most of the subjects exhibited moderate to severe physical disability in addition to disease conditions with serious prognoses. These disabilities were chronic at least in the sense that they had not been eliminated in the course of a hospitalization lasting more than

Table 3.3—Physical Disability

	No. of persons	Per cent of total
Activities of Daily Living <sup>1</sup> (Bathing, dressing, toileting, transfer, continence, feeding)		
Independent in all 6 activities	17	5.7
Independent in all but 1 or 2 activities	39	13.0
Dependent in 3, 4, or 5 activities	220	73.3
Dependent in all 6 activities	24	8.0
TOTALS	300	100.0
Walking		
Walking without personal assistance	83	27.7
Walking with personal assistance	167	55.7
Not walking	50	16.7
TOTALS	300	100.1
Strength and Range of Movement <sup>1</sup>		
Minimal or no disability	164	54.7
Moderate disability	43	14.3
Severe disability	93	31.0
TOTALS	300	100.0
House-Confinement <sup>1</sup> (During 2 weeks before hospitalization)		
Outside on 3 or more days	159	53.0
Outside on 1 or 2 days	43	14.3
Confined to house	98	32.7
TOTALS	300	100.0

<sup>1</sup>See definitions in Chapters 5 and 13.

five weeks on the average, during which rehabilitation was a major goal. A comparison of disability in this group with that in the general U. S. population may be obtained by comparing the data with the results of household interviews in the National Health Survey of the civilian, noninstitutional population in the United States (10). Between the ages of 45 and 64, 64 per cent reported that they had one or more "chronic conditions", and 20 per cent stated that they had some limitation in major activities such as working or keeping house. Over the age of 64, these figures rose to 81 and 49 per cent, respectively. In comparison, one-half to three-quarters of our sample needed assistance with

personal care or walking. Since the inability to walk or to care for personal needs implies greater degrees of dependency than does inability to work or keep house, it appears that most of the members of this study are more severely disabled than their contemporaries. For many, the goals of treatment must be sharply limited. Often, one thinks in such terms as eliminating the need for a night attendant or enabling the patient to manage by himself for a few hours rather than in terms of full physical independence and return to work.

#### *Socioeconomic Status and Function*

Patients referred to Abington House, which is a

voluntary institution without direct access to public funds (at the time of the study), are more likely to be those who have some personal financial resources. Patients in the same geographic area who are dependent upon public assistance are usually referred to a large chronic disease and rehabilitation hospital operated by the county. The subjects of the study, therefore, had generally more economic resources than those of a related study, who had been discharged from a municipal chronic disease hospital (8).

About one-third of these elderly, disabled people were married and living with a spouse, while more than a third were widows or widowers (widows predominating over widowers by more than 5 to 1). The remainder were divorced, separated, or never married (Table 3.4). The

presence of a spouse in the home is clearly an important resource when a patient needs personal assistance. Others, particularly children, may substitute for a spouse. The factor of household composition is, therefore, an important one to consider in interpreting results.

The sample shows a broad distribution in terms of social class, with a few more in the upper two classes according to the Hollingshead scale of social class than might be predicted from studies of the general population (Table 3.4). In a sample of households in New Haven, for example, Hollingshead found 12.4 per cent in Classes I and II, compared with 19 per cent here (11). Among the present subjects, 12 per cent were college graduates, and another 31 per cent had completed high school.

The "Index of Economic Dependence",

Table 3.4—Socioeconomic Status

	No. of persons	Per cent of total
<b>Marital Status</b>		
Married, living with spouse	111	37.0
Widow or widower	119	39.7
Divorced	24	8.0
Separated	3	1.0
Never married	43	14.3
<b>TOTALS</b>	<b>300</b>	<b>100.0</b>
<b>Social Class by Hollingshead Scale<sup>1</sup></b>		
I Professionals and executives	13	4.3
II Lesser professionals and executives	44	14.7
III Small businessmen, administrative assistants, clerical and white collar workers	64	21.3
IV Manual, skilled production workers	112	37.3
V Unskilled and semiskilled workers	67	22.3
<b>TOTALS</b>	<b>300</b>	<b>99.9</b>
<b>Index of Economic Dependence<sup>1</sup></b>		
1. Independent	22	7.3
2. Partially independent	111	37.0
3. Partially dependent	155	51.7
4. Dependent	12	4.0
<b>TOTALS</b>	<b>300</b>	<b>100.0</b>

<sup>1</sup>See definitions in Chapters 5 and 13.

which we describe in Chapter 5, is based (for the intake evaluation) on work status, home ownership, and source of economic support. Seven per cent were independent, meaning that they owned their own homes, were employed, and did not receive support from a charitable agency (Table 3.4). Most of the subjects, as might be expected from their age and disability, were not fully independent in these terms, although only four per cent were completely dependent in that they were not homeowners, were not employed, and were receiving agency support (exclusive of social security).

Examination of the economic factors in more detail showed that a fifth of the patients had worked up until the onset of the illness which led to this hospital admission, while two-fifths had retired within the preceding ten years. Considering the men only, 21 per cent had not worked for ten years or more, while the same was true of 58 per cent of the women. As has been demonstrated in other studies of the aged, women continued to function as homemakers longer than their spouses continued to work. Over half the individuals in the study (54 per cent) were active homemakers until the onset of their current illnesses. This figure included thirteen men.

One indication of the relative affluence of the subjects of this study is the fact that 63 per cent owned their own homes (or their spouse did). A majority (60 per cent) were receiving social security payments. Private sources of personal income, including pensions, annuities, and investments, were available in some measure to 83 per cent. Only 23 per cent received direct financial support from members of their families, and only 4 per cent from public or voluntary charitable agencies.

#### *Social Interaction*

The social environment of a person who is elderly, disabled, or chronically ill has a great deal to do with how his needs are met. The people in his household are potential providers of service. The degree to which he interacts with them and with more remote friends and relatives influences their availability as resources. The patient's interaction with his social environment

may also be altered by a treatment program. Because of the importance of such factors in the course of a continuing illness, we took particular care to define them and to describe them in objective terms at the beginning of the illness. Household composition, personal interaction, and regular social contacts and activities are summarized in Table 3.5.

In general, the subjects were integrated and interacting with their social environment. For comparison, in a study of 500 people over the age of 60 living on the East Side of Manhattan Island, 40 per cent were found to be living alone, whereas this was true of only 28 per cent of our sample (12). This proportion is comparable to the 25 per cent living alone found among people 60 and older in a working-class borough of East London (13). Two-thirds of the individuals in the study had daily contact with a spouse or relative and talked to three or more people daily. Like most older people, they had withdrawn somewhat from organized social activities; so that more than half reported that they did not regularly participate in churches, clubs, or the like. In the London study just referred to, 13 per cent reported that they went to church at least once a month, and 12 per cent belonged to a club.

The most common form of social relationship for these elderly, chronically ill individuals was with a spouse or child. Thirty-seven per cent lived with a spouse, and 28 per cent with a child or children. While 21 per cent reported daily contact with a nonrelative, only 8 per cent actually lived in a household with a nonrelative. This group as a whole exhibited a degree of family solidarity. Two-thirds had daily contact with a spouse, a child, or a relative. An indication of the extent to which these individuals maintained their social roles within the family is the fact that 61 per cent were reported to be the heads of the households in which they lived.

A group of patients of particular interest in this study were those who were relatively socially isolated and hence out of contact with ordinary sources of assistance. There were 28 per cent who lived alone, 20 per cent who reported no daily contacts with any other

Table 3.5—Social Interaction

	No. of persons	Per cent of total
<b>Household Composition</b>		
Married couple living with others	46	15.3
Married couple living by themselves	65	21.7
Solo* living with others	102	34.0
Solo living alone	85	28.3
Not living in a household or unknown	2	0.7
<b>TOTALS</b>	<b>300</b>	<b>100.0</b>
<b>Personal Interaction</b> (Daily contact with spouse, relatives, or friends)		
All 3 categories	8	2.7
Two categories	63	21.0
One category	165	55.0
No daily contact with anyone	59	19.7
Unknown	5	1.7
<b>TOTALS</b>	<b>300</b>	<b>100.1</b>
<b>Persons Talked to Per Day</b>		
10 or more	73	24.3
6-9	38	12.7
3-5	101	33.7
0-2	69	23.0
Unknown	19	6.3
<b>TOTALS</b>	<b>300</b>	<b>100.0</b>
<b>Regular Social Activities</b>		
More than one	61	20.3
One	73	24.3
None	164	54.7
Unknown	2	0.7
<b>TOTALS</b>	<b>300</b>	<b>100.0</b>

\*Solo means widowed, divorced, separated, or unmarried.

person, and 23 per cent who talked to two persons or fewer each day. There is considerable overlap among these three groups.

#### *Social Deprivation*

Townsend, in his study of old people living in London, makes a distinction between social isolation and what he terms "desolation", which is a feeling of loneliness, usually related to the recent loss of some accustomed social relationship (13). Individuals in such a condition may be

included among those identified above as being socially isolated. The isolated, however, also include those who, by habit or preference, have never associated much with other people. Because the most objective means of identifying the desolated is by recording recent losses, we have used the term "deprivation".

The three kinds of losses which we considered in the study were retirement from work, cessation of homemaking, and death of spouse. For death of spouse, we defined the period of recent

loss as 2 years. For retirement from work or cessation of homemaking, the 2-year period excluded the 30 days prior to admission to Abington House, since many patients who had worked or managed their homes within this recent period expected to return to their former activities and did not perceive the change as a loss, especially those who worked until the time of admission to the hospital. On the basis of the above definitions, 37.3 per cent worked or acted as homemakers during the 30-day period before admission to Abington House; and 30 per cent had never functioned in these roles or had withdrawn from them more than 2 years before admission. The remaining 32.7 per cent were defined as sustaining a recent loss in terms of these social roles. Slightly more than one-third of the patients (35.3 per cent) had experienced at least one of the three social losses considered here. Although these specific recent deprivations did not affect a majority of the subjects, three-quarters (222 patients) indicated that they had experienced a constriction of their social world, since they said that they talked to fewer people every day than at age forty-five. This finding may be compared with Cumming and Henry's report that two-thirds of a group of middle-aged and elderly people in Kansas City gave this answer to the same question, which they define as a measure of "perceived life-space" (14). Whether from a sociological point of view we consider these experiences as a diminution or a disengagement, they clearly reduce the number of available social roles and imply fewer regular social relationships which could serve as sources of assistance.

#### *Psychological Characteristics*

The psychological and mental function of a patient who enters a program for treatment of a disability may be one of the major determinants of his potential for improvement or deterioration. Although a public health nursing program is not directed primarily at the improvement of mental status, it does include treatment goals having to do with the patient's reaction to his illness, interactions among the members of his family, and his general psychosocial adjustment. Thus, we may look upon the psychological and

mental functions of the patients in this study as characteristics which limit or enhance the possibility of improvement and, to a lesser degree, as measures of outcome.

Many measures of intellectual and psychosocial function have been proposed, but few have been standardized for older populations (15). Tests such as the Wechsler Adult Intelligence Scale which have been so standardized are lengthy and not well adapted to use when much additional data must be collected (16, 17). We chose the following three measures which are described in Chapter 5: (1) a test of "orientation and mental control", consisting of standard questions such as "what is the date?" (2) a test of "observation and clear thinking" (Raven Progressive Matrices), consisting of sets of patterns to be matched, and (3) a rating of "psychosocial adjustment" made according to a standard distribution (Q-Sort) method. This last rating was done by observer members of the research staff at intake and was checked by an independent rating made by one of the physicians.

We summarize the results of these measurements in Table 3.6. They may be compared with a study of 208 patients (average age 60) discharged from the county chronic disease hospital referred to previously, in which these same measures were used (18). The patients in our study were oriented and functioning relatively well mentally, since three-quarters were classified as "clear", meaning that they made no more than four errors out of a possible eighteen on the test of "orientation and mental control". By contrast, only 52 per cent of the county hospital patients were found to be "clear". Only a small number in both studies were badly confused (2.0 and 8.0 per cent, respectively), while 16 and 22 per cent were partially confused in the two studies. A much higher proportion of patients were reported as untestable or untested in the county hospital series (18 per cent).

The test of "observation and clear thinking" showed that our subjects obtained scores in the upper and lower thirds of the range more frequently than did those discharged from the county hospital. In the latter study, however, about twice as many were found to be

Table 3.6—Psychological Characteristics

	No. of persons	Per cent of total
Orientation and Mental Control <sup>1</sup>		
Clear (14-18)	235	78.3
Partially confused (5-13)	49	16.3
Confused (0-4)	6	2.0
Unknown	10	3.3
TOTALS	300	99.9
Observation and Clear Thinking (Raven) <sup>1</sup>		
Good (28-36)	62	20.7
Average (9-27)	181	60.3
Poor (0-8)	18	6.0
Unknown	39	13.0
TOTALS	300	100.0
Psychosocial Adjustment Rating <sup>1</sup>		
Good (16-40)	154	51.3
Average (42-66)	78	26.0
Poor (68-92)	38	12.7
Unknown	30	10.0
TOTALS	300	100.0

<sup>1</sup>See definitions in Chapters 5 and 13.

untestable ("unknown"). The median score for our subjects was 20.7, which is very close to the median score of 20 for "normally healthy old people" (average age 75 years) reported by the authors of the test (19).

The ratings of "psychosocial adjustment" offer difficulties in interpretation. Comparison of the ratings made of the same patients at intake by physicians and observers showed certain disparities, with identifiable biases toward higher or lower ratings associated with different raters. The ratings in Table 3.6 are those made by the nonphysician observers. The range of possible adjustment scores is presented with the upper and lower fourths separated from the middle half. On this basis, the subjects of our study, compared with those in the county hospital study, showed roughly similar proportions in the good, average, and poor adjustment groups.

In summary, most of these elderly, disabled individuals were able to function on a mental

and psychosocial level not greatly different from others of their age and probably somewhat better than the average for patients discharged from a county chronic disease hospital. Relatively small groups of persons had distinct limitations in mental and psychosocial functions.

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## CHAPTER IV. PROVIDING CONTINUED CARE

Home nursing care for patients in the treatment group was given by the Visiting Nurse Association of Cleveland (VNA). This is one of about 1800 agencies certified by the United States Public Health Service to provide home health services under Title XVIII, Public Law 89-97. Of the 1800, slightly more than thirty per cent are visiting nurse agencies. In this chapter, we describe the Cleveland agency and, then, discuss nursing visits in the research program.

### *The Visiting Nurse Association (VNA)*

The VNA is a voluntary public health nursing agency which has offered services in the Greater Cleveland area for more than sixty years. Initially organized to provide care for the sick in their homes, its functions were soon expanded to include prevention of illness and promotion of health. The agency serves a population of a little over one million for whom services are also provided by six health departments and numerous boards of education. The caseload includes patients from a wide variety of social, cultural and economic groups. Financial support comes from the United Appeal, endowments, other voluntary health agencies, and fees.

The VNA Board of Trustees, a citizen group of forty members, has full responsibility for the management and control of the Association. They have directed the affairs of the agency with a keen awareness of new developments in the health field, accepted and promoted changes in the interest of progress, and undertaken new responsibilities with enthusiasm tempered with thoughtful study. Further community participation comes through a public relations committee with representation from various geographic areas, racial, and ethnic groups. This committee is responsible for interpreting the service, for obtaining reaction of the community to the

service, and for offering recommendations for strengthening the program.

In 1966, when the number of study patients receiving service was at its peak, the staff included:

#### Nurses:

Nursing Administrative Staff:	
Director and Assistant Director	2
Supervisors	4
Home Care Coordinator	1
Staff Nurses:	
Fully qualified (with college preparation)	41
Diploma graduates	12
Licensed Practical Nurses	5

#### Consultants:

Medical (part time)	1
Psychiatric (part time)	1
Physical Therapists (2 part time)	3
Occupational Therapist (part time)	1
Social Work (part time)	1
Nutrition (part time)	1

Comptroller	1
Secretaries and clerks	13

Responsibilities are assigned to nurses according to levels of preparation and demonstrated ability. A continuous effort is made to enable the qualified nurse to devote a maximum amount of time to those patients and families for whom, in the judgment of the nurse and supervisor, comprehensive nursing care holds potential value. Various methods are employed for using, in a team relationship, the qualified public health nurse, graduate of a diploma nursing school, licensed practical nurse, and home health aide.

The VNA staff development program is designed to help each nurse progress on an individual basis according to her ability. It is based on the philosophy that people learn and

develop best in an atmosphere which is conducive to creative thinking and freedom of expression and which provides opportunity for nurses to participate in planning and policy making. An organized staff education program includes group and individual conferences. Supervisors are required to have a master's degree from a program providing work in administration and supervision. They devote approximately fifty per cent of their time to individual conferences with nurses. Physical therapists function in a consultant capacity, assisting nurses with the physical rehabilitation aspects of their work. They visit for demonstration and supervision of exercises that are carried out by nurse, patient, or family. Social workers, nutritionists, and two physicians, one a psychiatrist, also provide consultant services.

The agency fee is based on average cost per visit with adjustments made when the family cannot meet the full payment. Since our intent was to have the process in the research program conform as much as possible to ongoing practice, we decided to charge the usual fee. However, to eliminate the possibility of having cost influence acceptance of service, we advised the nurses to waive fees for study patients when in doubt about family willingness to pay for services. Fifty-three or approximately one-third of the patients in the care group paid a fee. Four of the fifty-three paid full fee for all visits. Twelve paid full fee for part of the service, and thirty-seven paid partial fee for all or some visits. Determination of the patient's fee status was an integral part of evaluation and planning for care and often not established until several visits had been made.

Care and rehabilitation of the sick is a primary function of the VNA and is given with an ever-widening perspective of the nurse's responsibility as therapist, health counselor, and coordinator. In recent years, the agency has intensified efforts to make available related services, including those of the homemaker and home health aide, occupational therapist, speech therapist, dentist, and caseworker. Few, if any, patients receive as much service as they need because of limitations in financial support and qualified personnel. The amount of service given

each patient is determined with consideration for its potential value, the complexity of the problem, interest in care as demonstrated by patient and family, and the importance of nursing and related health services to the total treatment plan. When giving care to patients in their home environment, it is essential that consideration be given to the family as a unit and with focus on the problems which are of major concern and interest to them. Nursing care encompasses psychological, social, cultural, and economic factors. Coordinated planning, when a multiplicity of professional personnel are involved in the care, not only makes possible common goals and greater economy in the use of professional time, but also results in sounder judgments on the part of each person who is contributing to the care (1).

We specified in the research design that public health nursing care would be given in the usual service setting with four special provisions:

- 1) Nurses would be selected to participate in the care program from those who had demonstrated ability to provide comprehensive care and expressed interest in taking part. In the interest of continuity of care, priority would also be given to those who expected to remain in the employ of the agency.
- 2) All patients would be followed for 24 months and would receive visits as needed with a minimum of one every three weeks for the first 12 months and one every six weeks thereafter.
- 3) A special record system designed to describe nursing service would supplement the agency case records. Activity records would be completed at the conclusion of each visit, and service given described under broad categories of function. Narrative reports would give information about patient progress, goals in care plans, problems, social and physical environment, and contacts with physician and other members of the care team.
- 4) A public health nurse coordinator would be employed to serve as liaison between the investigators and the agency personnel.

Continuity of care and minimal changing of

nurses is the usual practice in the VNA, but particular effort was made to maintain this standard for our research patients. Of the 150 patients visited, 100 were assigned to the same nurse throughout their care; 38 had two nurses; 11 had three; and one had four. Changes in nurses were explained by resignations of nurses and changes in residence of patients when distance made it completely impractical for the same nurse to continue care.

Although care was given by only a small proportion of the staff, participation in the study was a total agency project. The Board of Trustees, in the spring of 1962, paved the way by devoting a Sixtieth Anniversary luncheon program to the role of the agency in research. All staff nurses were kept abreast of plans, and the VNA nursing administrative staff and nurse coordinator for research took responsibility for policies and helped design research record forms. The nurse coordinator consulted with supervisors and staff about special records, patient visits, and referral procedures, while supervisors maintained responsibility for staff guidance related to patient management.

Since the VNA staff frequently participated in special projects, we anticipated that the experienced nurse would assume her additional responsibilities for research patients without special difficulty. However, the following problems were not anticipated and were of real concern to the nurses. Two days before discharge, physicians on our research staff explained reasons for referral to the nursing program to patients and families, and this timing occasionally restricted the amount of discharge planning. A very few families had already employed a practical nurse or attendant, while some family members who had come to the hospital for instructions felt capable of giving care independently. The nurse on her first visit sometimes found a family fearful that the VNA referral reflected on their ability, and a few patients in the study lacked conviction that follow-up care was needed.

Although two nurses were added to the staff, referral of research patients could not be spread evenly, occasionally resulting in peak loads and necessitating deferment of visits to nonresearch

patients. Nurses also had to make the adjustment of conforming to our research design which specified the minimum number of visits they were to make during stated intervals, when they had been accustomed to making independent decisions based on the needs and interest of patients.

The special "activities record" required the nurse to analyze each aspect of a single visit and record her various activities and functions under specific categories. Although recording is an accepted public health nursing function, some nurses found the special records difficult. Most of the nurses, however, reached the conclusion that the research records helped them to plan care more systematically. Supervisors commented on the value of the activity records in helping nurses to analyze situations in a more orderly manner. This value, the supervisors believed, was carried over into other cases.

As we noted previously, the supervisors and coordinator assisted the staff with the special responsibilities for research patients. Group conferences with other members of the research staff helped the nurses gain a more thorough knowledge and understanding of the research goals, to feel a part of the total program, and to overcome fears and conflicts. Nurses had the opportunity to share their problems and approaches to patient care with emphasis upon increased understanding of the aging, the chronically ill, and their families. We stressed the importance of their nursing contribution, and the nurses increased their appreciation for the value of long term supervision of patients who have a chronic illness—less often possible in their regular caseload because of too few staff. They gained a fuller understanding of the meaning and components of rehabilitation for elderly people in their home settings. They also believed that the study offered them an opportunity to make a contribution to their profession. The nurses' statements referring to the study changed from the "hospital's research" to "our research".

Our decision to test the study hypothesis in the usual service setting had the practical advantages of an organized service with established procedures for interagency cooperation and coordination, personnel meeting recommended

qualifications, administrative structure that met recommended criteria, affiliation with other community agencies, and an organized staff education program directed by qualified supervisors and consultants. Participation in the study was of value to the agency. Though we did not design the study to examine all public health nursing contributions to patients with chronic illness and to their families, an opportunity was provided for systematic examination of a broad range of potential contributions. This joint endeavor by physicians and nurses is of special significance because of the urgent need for more comprehensive understanding about the needs of the sick in their homes. This understanding is essential for sound community planning and effective use of health personnel at a time when demands for care are growing at a rate far in excess of available resources.

*Service by Visiting Nurses in the Research Program*

The major concern of our study was the comparison of outcomes in the nursed group with those in the non-nursed group. Accordingly, it was necessary to be satisfied that those in the nursed group actually did receive nursing care and that those in the non-nursed group did not, before accepting seriously any conclusions about differences in outcome between these two groups. We expected that some degree of nursing care would be sought by the non-nursed group since, as was mentioned earlier, about 14 per cent of patients discharged from Abington House had, in previous times, been referred to the VNA. Occasionally, also, patients who were discharged from the hospital sought nursing assistance independently. Not all of those assigned to the nursed group received nursing care since a few patients were unwilling to cooperate with nurses and since a few died shortly after discharge from the hospital. If the expectations of the research design were met, we would have expected every one of the 150 patients in the nursed group to receive at least one visiting nurse visit and none of the 150 patients in the non-nursed group to receive any visit. A crude measure of the degree of adherence we actually observed is given in Table

4.1, which summarizes the overall two-year experiences of the patients in this regard. The information in the table indicates that nonadherence in the nursed group was slight (5/150), while nonadherence in the non-nursed group was somewhat greater (34/150).

The 34 in the non-nursed group who received nurse visits had, with little doubt, different characteristics from the 116 who did not receive visiting nurse visits. Their elimination from the non-nursed group would, thus, constitute a selection bias of unknown magnitude in any comparison of outcome between the two groups and would prevent any meaningful interpretation of results. On the other hand, if the original randomization assignments are accepted, an equivalent proportion (34/150) of spontaneous referrals to the VNA would be expected in the nursed group if this group did not receive assigned nursing visits. This is true by virtue of the randomization process and the laws of probability which apply thereto. Since the two originally randomized groups are comparable with regard to the likelihood of spontaneous referrals to the VNA, the original random assignments to the experimental groups were strictly followed in all comparisons of outcome throughout this report.

The amount of nonadherence to the study plan was not as large as might be inferred from Table 4.1 since, in this table, a person receiving only one visit is given the same weight as a

Table 4.1—Numbers of People Receiving Visiting Nurse Visits During the Study

Experimental Groups	At least one nurse visit	No nurse visit	Totals
	(number of persons)		
Referred to Visiting Nurse (N+)	145	5	150
Not Referred to Visiting Nurse (N-)	34	116	150
Totals	179	121	300

person receiving 100 visits. In terms of total numbers of visits during the study, the nursed group received 5667 visits, and the non-nursed group received 834 visits. The frequency distribution which we present in Table 4.2 contrasts the total number of visits per person in the nursed group with the total number of visits in the non-nursed group. In the nursed group, the most frequent range of total visits was 21 to 40 visits per person, while the most frequent range was 1 to 5 visits per person in the non-nursed group.

We consider, next, the extent to which visiting nurse follow-up was sustained. There were 89 persons in the nursed group still available for nursing visits (i.e., alive and not in a nursing home) at the end of the study, and there were 91 such persons in the non-nursed group. In Table 4.3, we summarize nursing visits among those available for visits at the end of the study. Information in the table reveals that, at the end of the study, 64 persons in the nursed group were still receiving visits, while only 2 were receiving visits in the non-nursed group.

From studying Tables 4.1, 4.2, and 4.3, we conclude that (1) the number of people in the nursed group who received nurse visits was much greater than the number in the non-nursed

Table 4.2—Distribution of Patients According to Number of Nurse Visits During the Study

Number of nurse visits during the study	Experimental Groups	
	Referred to Visiting Nurse (N+)	Not referred to Visiting Nurse (N-)
(range)	(number of persons)	
0	5	116
1-5	21	11
6-10	10	8
11-20	27	3
21-40	36	6
41-60	23	1
61-80	9	2
81-100	10	1
101+	9	2
TOTALS	150	150

Table 4.3—Numbers of Persons Receiving Visiting Nurse Visits Among Those Available for Visits at the End of the Study

Experimental groups	Receiving visits	Not receiving visits	Totals
	(number of persons)		
Referred to Visiting Nurse (N+)	64	25	89
Not Referred to Visiting Nurse (N-)	2	89	91
Totals	66	114	180

group; (2) of those receiving visits, the people in the nursed group received more visits per person than those in the non-nursed group; and (3) the nursing care follow-up was more sustained in the nursed group than in the non-nursed group.

The fact that there were large differences in nurse visits between the nursed and non-nursed groups is further strikingly demonstrated by examining Figures IV-1 through IV-6. In these Figures, nurse visits are presented graphically for each patient of a 2-year horizontal time axis. Breaks in the horizontal time bar indicate intervals of time when patients were not available for visits due to death, hospital stay, nursing home stay, move out of the VNA service area, or withdrawal from service by mutual consent between the patient, his family and the nurse. Figures IV-1 through IV-3 present the graphs of nurse visits for patients in the nursed groups, and Figures IV-4 and IV-6 present the graphs for the non-nursed group. We classified patterns of visits of the graphs as high, medium, or low frequency patterns, where the frequency of visits was defined as the number of visits in the 2-year study period divided by the number of days available for visits in the 2 years. A frequency of at least 0.10 was called "high" and corresponded to at least one visit every 10 days, on the average. A frequency between 0.10 and 0.05 was called "medium". A frequency of less than 0.05 was called "low" and corresponded to less than one visit every 20 days, on the average.

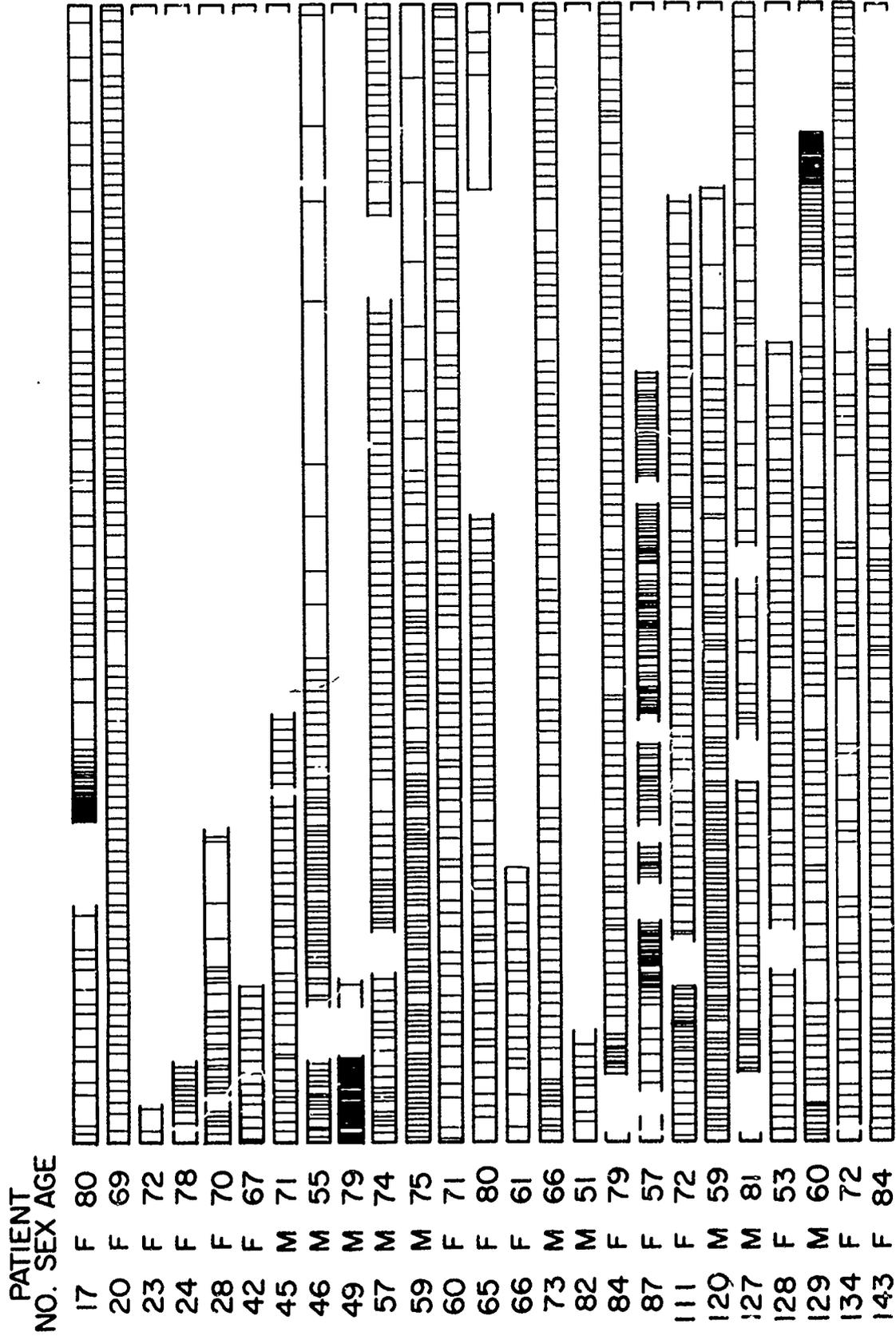
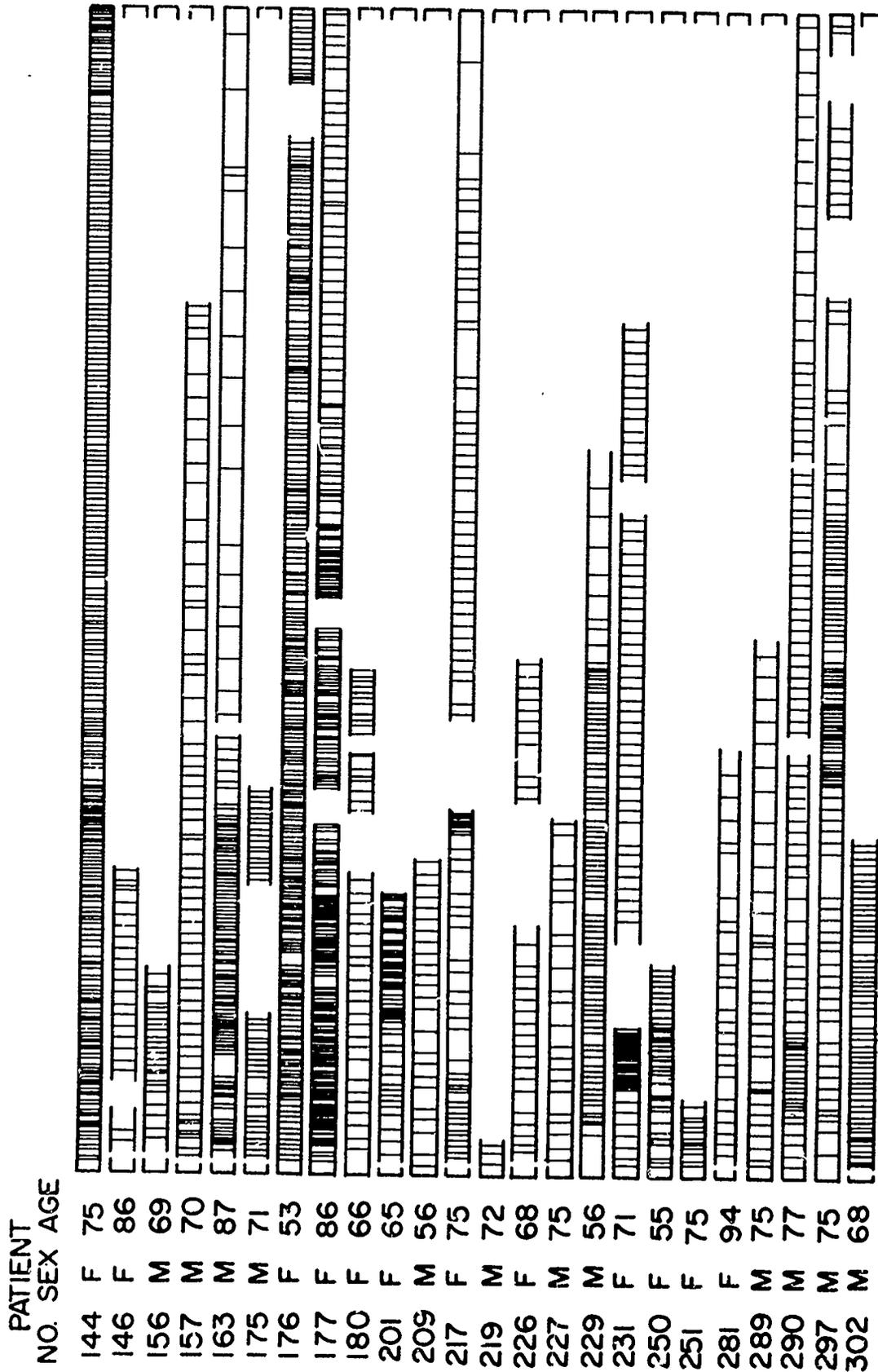


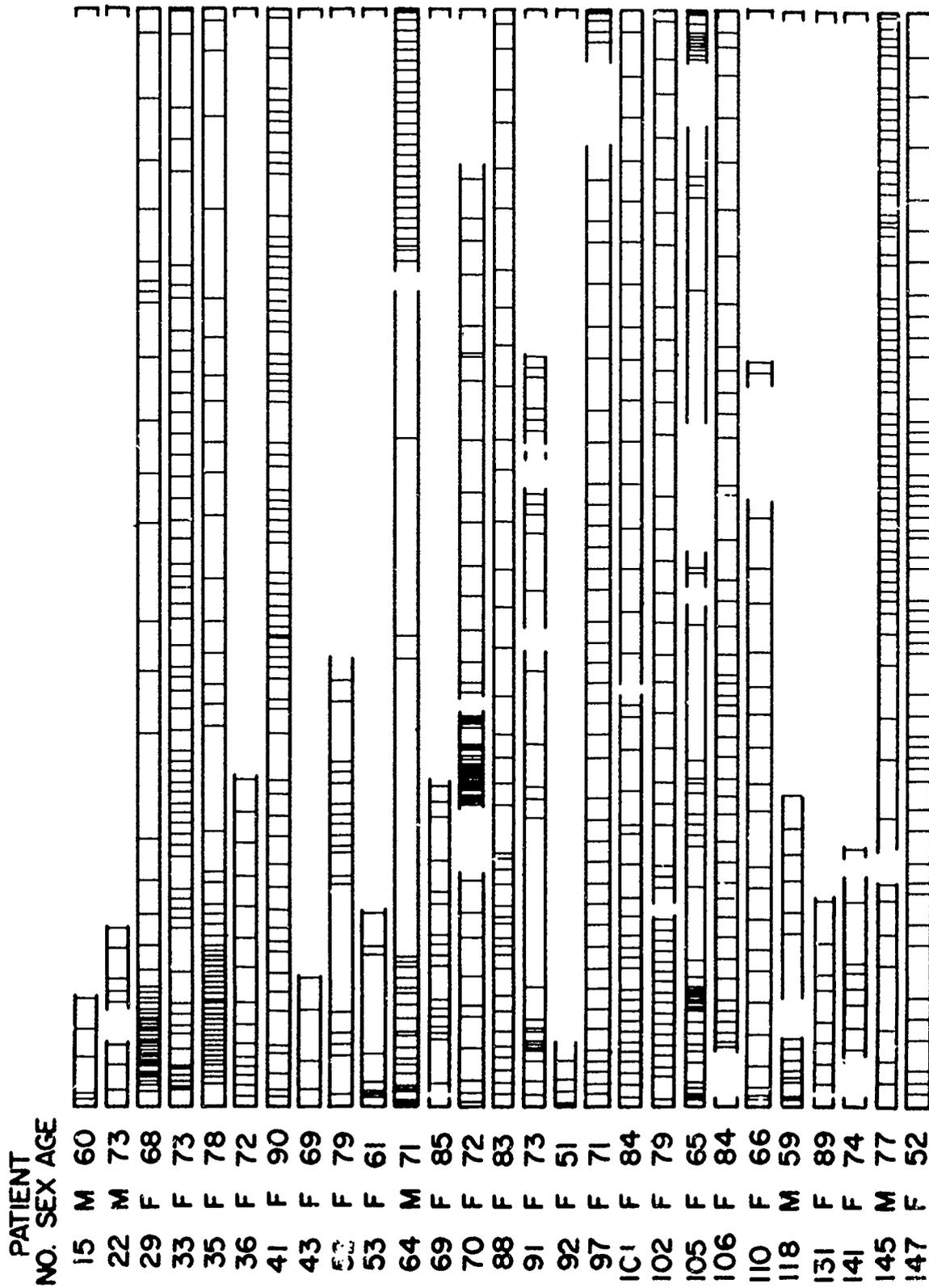
Figure IV-1. Patients in Treatment Group with "High Frequency of Visiting Nurse Visits"<sup>1</sup>





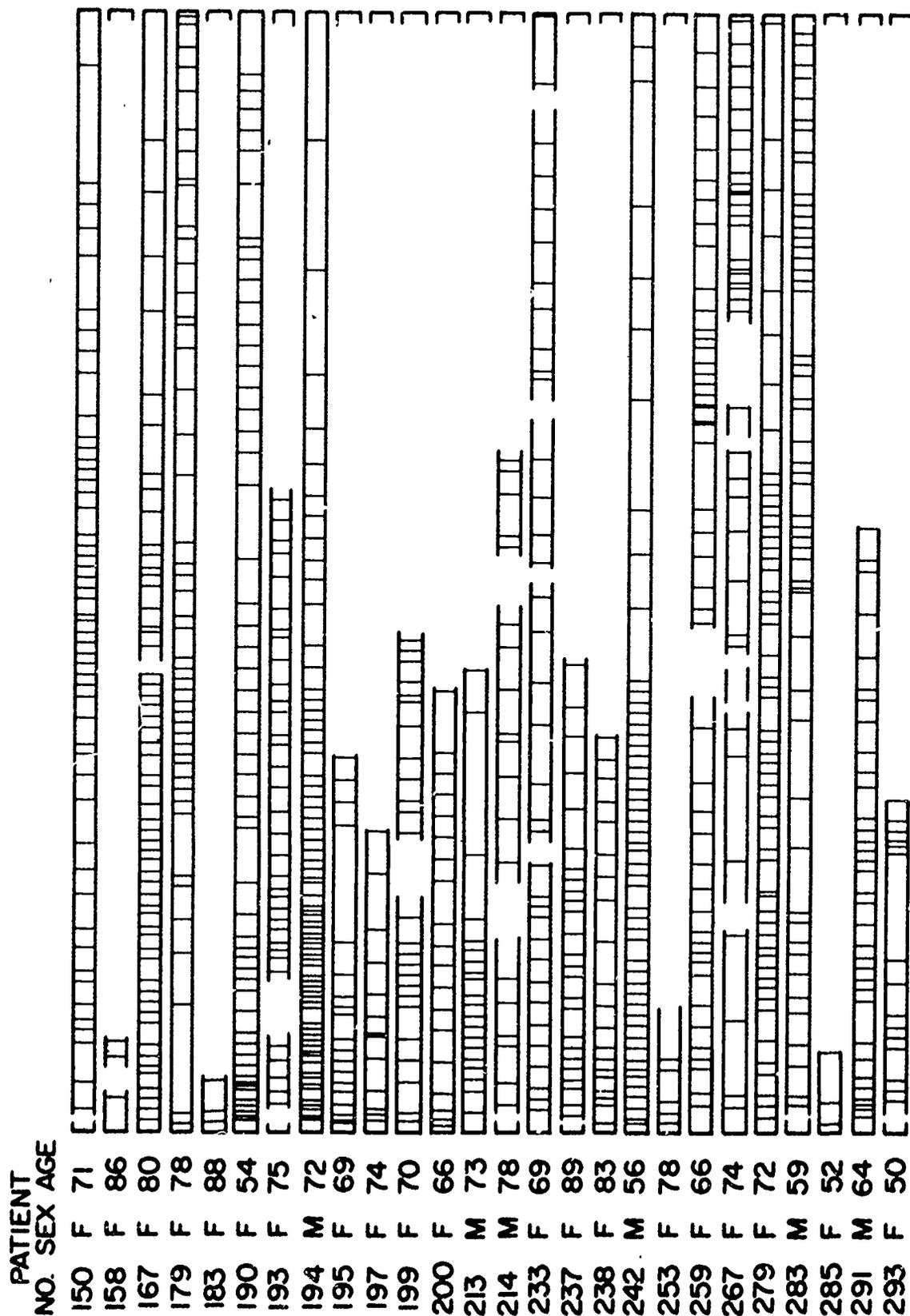
Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "High frequency of visits" was defined as at least one visit per 10 available days (on the average).

Figure IV-1 (cont'd). Patients in Treatment Group with "High Frequency of Visiting Nurse Visits"<sup>1</sup>



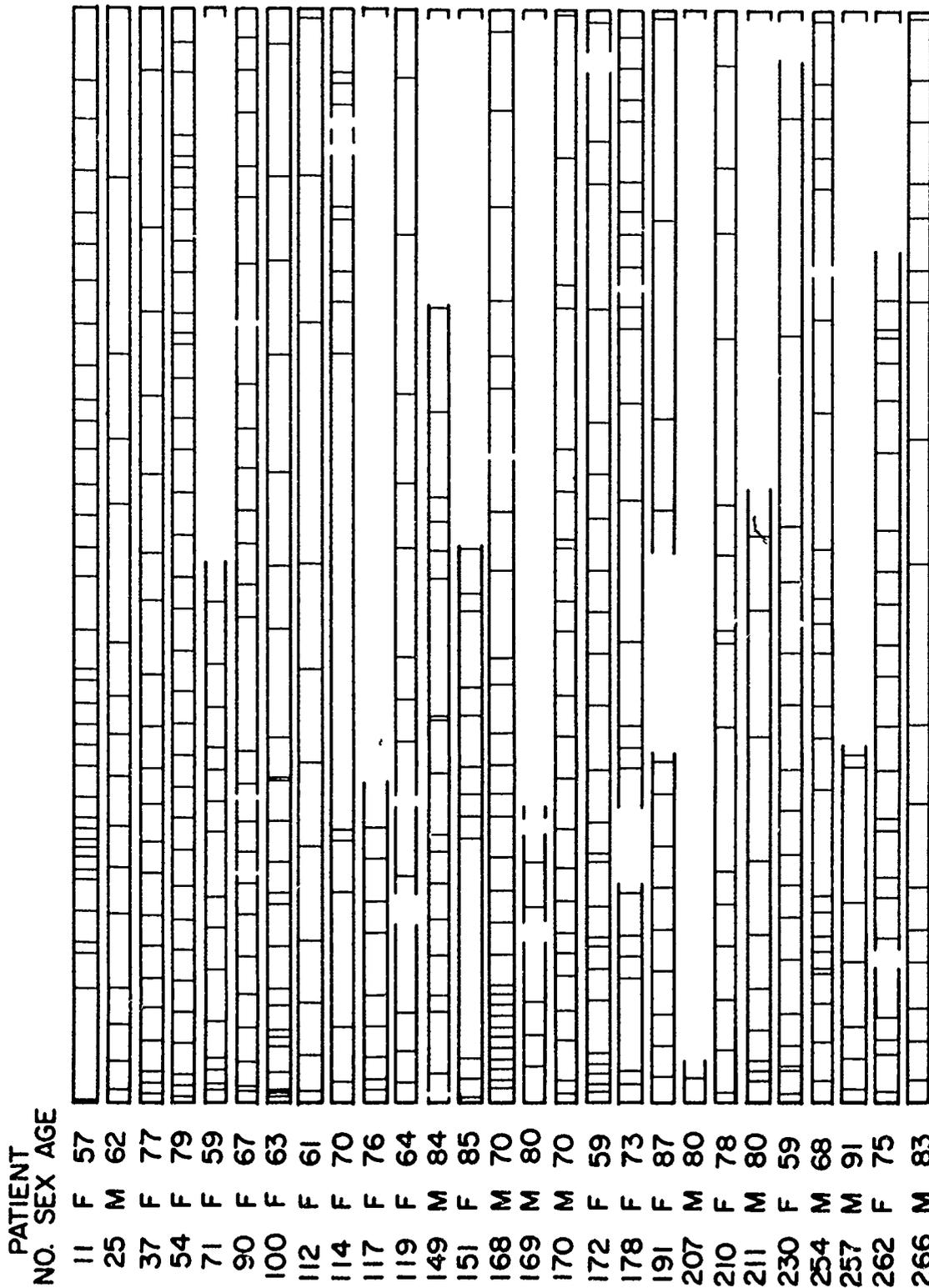
Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "Medium frequency of visits" was defined as one visit per 11 through 20 available days (on the average).

Figure IV-2. Patients in Treatment Group with "Medium Frequency of Visiting Nurse Visits"<sup>1</sup>



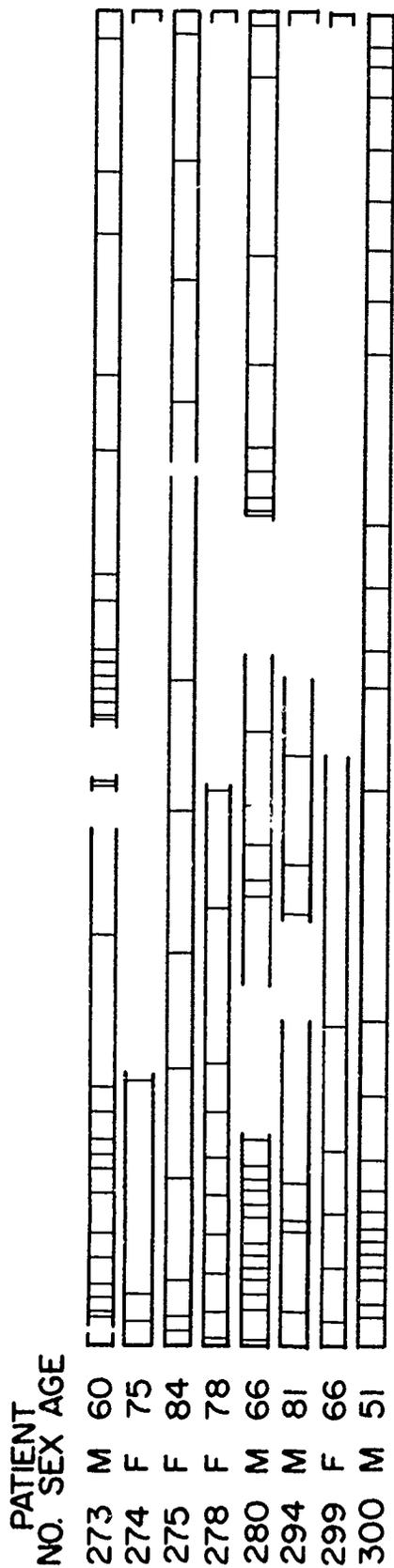
Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "Medium frequency of visits" was defined as one visit per 11 through 20 available days (the average).

Figure IV-2 (cont'd). Patients in Treatment Group with "Medium Frequency of Visiting Nurse Visits"<sup>1</sup>



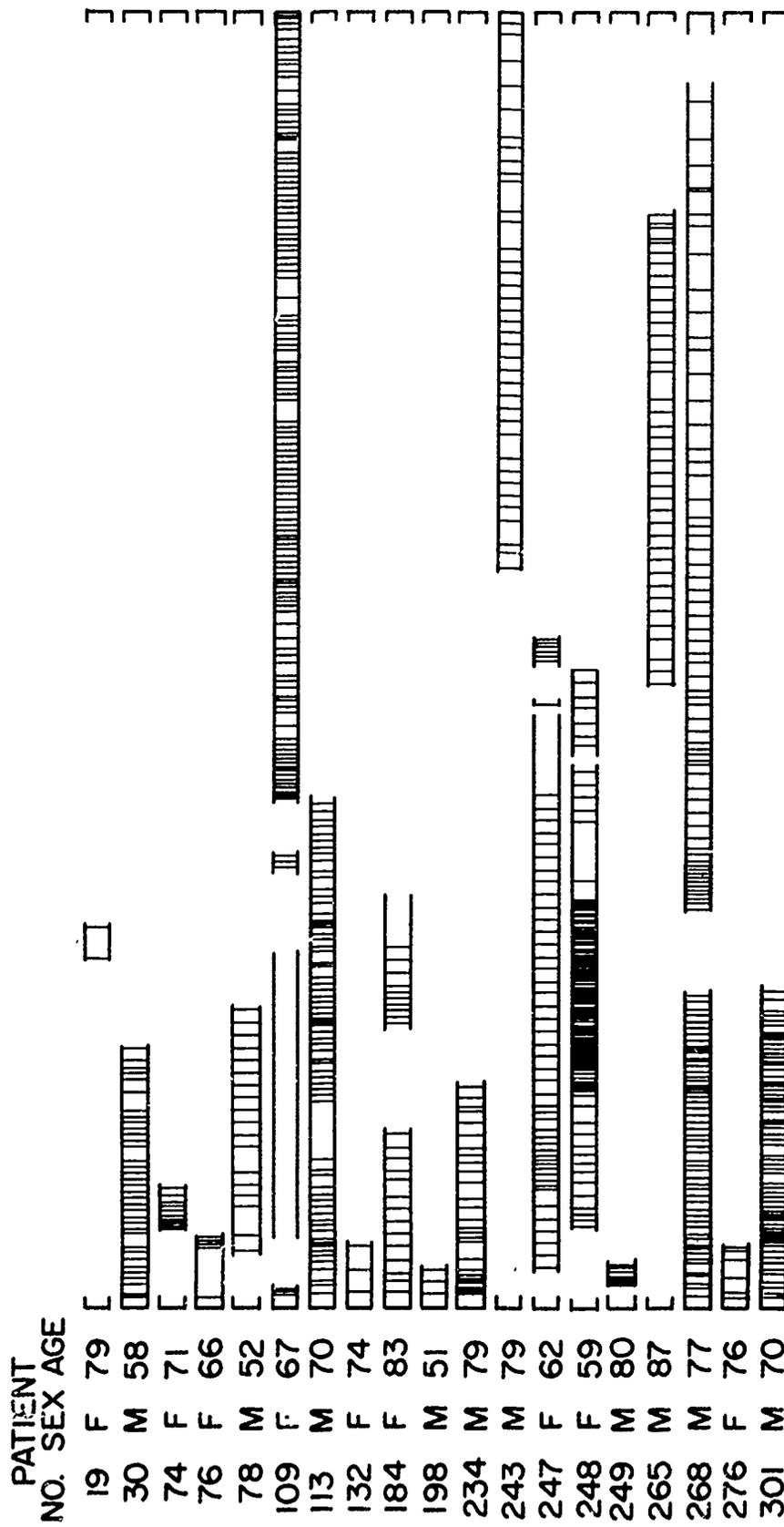
Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "Low frequency of visits" was defined as less than one visit per 20 available days (on the average).

Figure IV-3. Patients in Treatment Group with "Low Frequency of Visiting Nurse Visits"<sup>1</sup>



Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "Low frequency of visits" was defined as less than one visit per 20 available days (on the average).

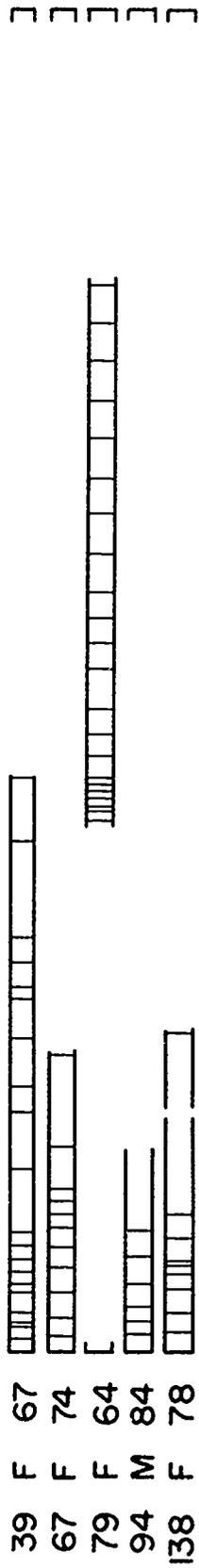
Figure IV-3 (cont'd). Patients in Treatment Group with "Low Frequency of Visiting Nurse Visits"<sup>1</sup>



Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "High frequency of visits" was defined as at least one visit per 10 available days (on the average).

Figure IV-4. Patients in Control Group with "High Frequency of Visiting Nurse Visits"<sup>1</sup>

PATIENT  
NO. SEX AGE

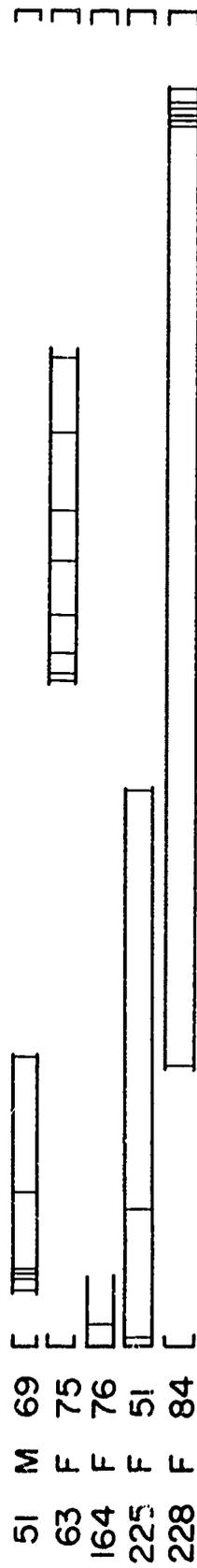


1 Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "Medium frequency of visits" was defined as one visit per 11 through 20 available days (on the average).

Figure IV-5. Patients in Control Group with "Medium Frequency of Visiting Nurse Visits"<sup>1</sup>

Effects of Continued Care

PATIENT  
NO. SEX AGE



Each vertical line represents a nurse visit along the 2-year horizontal time axis. Breaks in the time bar indicate unavailability for visits because of hospital stay, nursing home stay, move out of VNA area, refusal, or death. "Low frequency of visits" was defined as less than one visit per 20 available days (on the average).

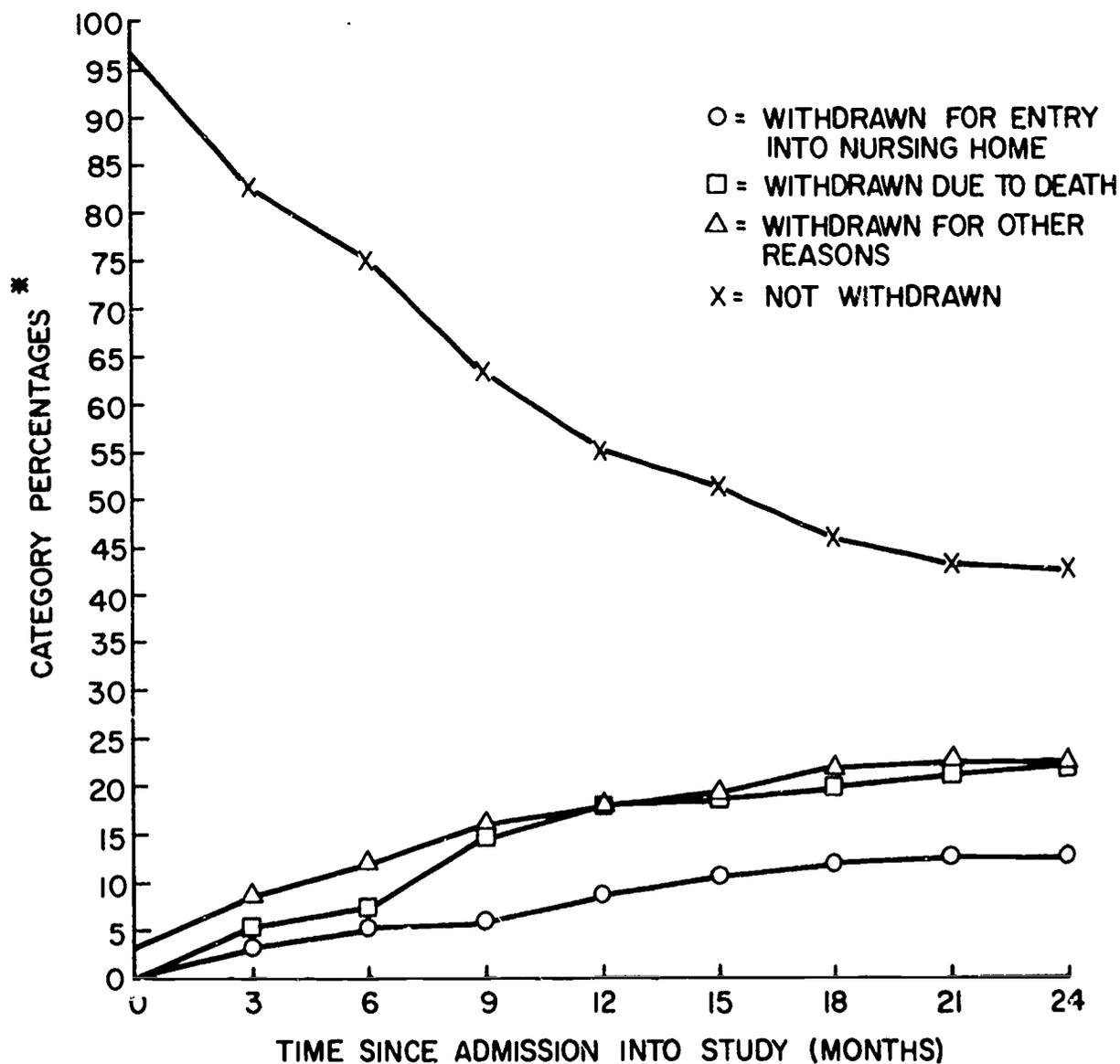
Figure IV-6. Patients in Control Group with "Low Frequency of Visiting Nurse Visits"<sup>1</sup>

Effects of Continued Care

Patients who were never visited or who had fewer than 10 available days for visits during the study were considered ineligible for frequency classification (13 in the treatment group and 121 in the control group); therefore, graphs for such patients are not included in the figures. In the nursed group, the frequency of nurse visits over the entire 2-year period was high in 49 patients, medium in 53, and low in 35. In the non-nursed group, the frequency of visits was high, medium, and low in 19, 5, and 5 patients, respectively. The remaining patients in each

group were either never visited or had fewer than 10 available days for visits.

For patients in the group assigned to the nursing program, we illustrate the decreasing proportion of those receiving nursing services in Figure IV-7. The decreasing proportion is explained by withdrawals from the nursing program by reason of death, admission to nursing homes, and other reasons as graphed in the same Figure. At the end of the study, 42.7 per cent of these patients were still receiving nursing services: 12.7 per cent had withdrawn



\*The denominator for these percentages is the 150 patients who were assigned to the nursing program (N+ group)

Figure IV-7. Withdrawal from Nursing Program

because of entering nursing homes: 22 per cent had withdrawn by reason of death; and 22.7 per cent had withdrawn for other reasons. Among the latter, 6 patients had moved out of the area of VNA jurisdiction, and 5 had never received nursing services.

#### *Extent of Nurse Follow-ups (Examples)*

*Patient number 36* was hospitalized in Abington House for rehabilitation after sustaining a unilateral fracture of the tibial plateau. She was 72 years old, had never been married, and had retired about 9 years earlier from her position as a buyer and seller of children's books for a locally well-known book and antique store. She was relatively isolated socially and obtained financial assistance from Social Security and from a local private philanthropic social agency. After discharge from Abington House, VNA visits were initiated. A cleaning woman also helped her at home. The patient complained increasingly of gastrointestinal discomfort. She became more isolated, expressed dissatisfaction with the nurse, and was concerned about death. After a period of about 7 months in which she received 15 nurse visits, she had an episode of hemoptysis and was rehospitalized. A gastric resection was performed for carcinoma. Complications ensued, including intestinal obstruction and myocardial infarction; and the patient died.

*Patient number 87*, a 57-year-old housewife with rheumatoid arthritis, was assigned to VNA assistance in the home after being discharged from rehabilitative treatment in Abington House. Though unable to do heavy housework, she was independent in self-care except for some assistance in bathing. Her husband, also partially disabled, could not assist; and the patient moved from her own home to the home of a married son. For 16 months, an active program of nursing assistance was maintained, in which she received 130 visits. The program was interrupted only by five short-term hospitalizations. The nursing visits supplied intensive assistance in such areas as exercises, prescribed medication, tub bathing, and psychosocial care. At the end of 16 months, nurse visits were terminated since the patient moved out of the state and, thus, out of the VNA service area. The move was made to

the home of an unmarried son, where her husband also lived.

*Patient number 92*, a 51-year-old housewife, had been admitted to Abington House for rehabilitation after a stroke. Prior to the stroke, she had been an active homemaker, taking care of two adolescent children and participating in ceramic, investment, and social clubs. Her husband was independently wealthy and employed full time practical nurse assistance in the home when the patient left the hospital. The patient's sister also helped, and the VNA nurse attempted to establish a coordinated program of assistance within the home. The patient was aphasic and walked with the aid of a short leg brace and quad cane. The family was unable to adjust to her disability, and she was admitted to a nursing home within six weeks after discharge from Abington House. During the 6-week period after discharge, she received four nurse visits.

*Patient number 200* was a 66-year-old widow with 2 married daughters. She had become widowed 22 years earlier and had been successful in both business and purposeful social activities. Two years before admission to Abington House, she had developed paraplegia of unknown cause and had narrowed her business activities to clerical work at home. After discharge from Abington House, she received VNA assistance (19 visits) for about 10 months in relation to skin care, catheter care, and a prescribed program of exercise. A physical therapist also came into the home on occasion, and her daughters visited regularly to assist with housekeeping. Though she made a determined effort to maintain her strength and independence, the paralysis became noticeably worse three months after she left the hospital. She continued a downhill course physically, but remained alert mentally. She had to move to the home of a married daughter 10 months after discharge. Since her daughter's home was out of the area of the VNA service area, VNA visits were discontinued; and five months later, the patient chose to enter a nursing home.

*Patient number 52* was 79 years old and a widow of 20 years duration. In Abington House, she received treatment for an intertrochanteric fracture of the right hip and for arteriosclerotic

heart disease with chronic congestive failure and angina pectoris. A self-employed dressmaker until age 69, her income was from past savings. She had no children or relatives and had been living a relatively isolated life due to age, illness, and mild mental confusion. She lived in an apartment and expressed fears about going out alone. She received 18 nurse visits during a 10-month period after discharge from Abington House and was also assisted by a home aide for two or three days each week. The nurse devoted much effort to supervision of medication and attempted unsuccessfully to coordinate care for the patient. Physician visits were spaced irregularly, partly as a result of the patient's inability to hear telephones and doorbells. She did not adjust well to her illness and voiced many complaints. Because of dissatisfaction with her physician, she went to a hospital outpatient clinic. In the clinic, she also had many complaints. She sought out another private physician and complained about the financial burden of private care. After 10 months at home, she suffered a heart attack, was hospitalized, and died.

*Patient number 226* was a 68-year-old lady who had never been married and who had retired from clerical work 9 years earlier. She and an unmarried sister with whom she lived had no outside interests and were very dependent on each other. Financial support came from Social Security and from a philanthropic social agency. In Abington House, the patient was treated for stroke, fracture of the wrist, arteriosclerotic heart disease, and mild diabetes mellitus. She was not paralyzed, but was demented and incontinent. For about 10 and one-half months after discharge from the hospital, she was visited by the VNA nurse. The nurse, in 29 visits, dealt primarily with problems of adjustment to illness, assisting also with medications, bathing, and exercise. These visits were interrupted by a temporary period of care in a nursing home at a time when her sister was ill. The patient had a second stroke ten and one-half months after discharge from Abington House. She was rehospitalized for three weeks, remained semi-comatose, and was discharged to care in a nursing home. After one more hospitalization

for bronchopneumonia, she died in the nursing home, having lived a total of about three months after the occurrence of the second stroke.

\* \* \* \* \*

We classified nursing activities for the study as those concerned with exercises, prescribed treatments, activities of daily living and mobility, health promotion, psychosocial care, and planning and coordination. In particular, the activities which we recorded systematically were those which reflected assistance to the patient, the family, and, in the case of planning and coordination, other service personnel. The following are but a few examples of the many combinations of services and activities which were recorded. Certain patients were helped with physical exercises while others were instructed in exercises. The families of many patients received instructions about exercises, diet, or prescribed oral medication. Nurses administered parenteral medication, performed irrigations, and changed dressings. They assisted patients with bathing and instructed families about bathing procedures and about other activities of daily living, including also ambulation and stair-climbing. Health promotion activities included instruction and assistance with problems in such areas as nutrition, accident prevention, hygiene, and recreation. Nurses helped patients and families identify such psychosocial problems as reactions to illness, grief, interpersonal difficulties, and economic problems. In the area of planning and coordination, nurses communicated on behalf of the patients with occupational therapists, physical therapists, physicians, social workers, and personnel in many other community agencies.

We analyzed the amounts of nurse services and changes in nurse services over time in terms of the proportion of patients and/or families involved in any given service from among those eligible to receive nursing services within a defined interval of time. On this basis, more than 90 per cent of eligible patients in the nursed group received nurse assistance in the following areas during the first three months of the study: activities of daily living (including

also mobility), health promotion, planning and coordination, and psychosocial care. In the case of health promotion and psychosocial care, the proportion of patients receiving such assistance remained greater than 90 per cent throughout all the quarterly intervals of the two years of study. In the case of activities of daily living (including also mobility), the proportion receiving assistance decreased slightly, but remained greater than 80 per cent throughout the study. The proportion receiving assistance in planning and coordination decreased to 69 per cent in the second three months of the study and varied between 49 and 61 per cent thereafter. At the beginning of the study, the proportions of patients who were assisted with oral medications, prescribed treatments, and exercises were 75 per cent, 61 per cent, and 56 per cent, respectively; and, by the end of the study, these proportions dropped slightly to 59 per cent, 45 per cent, and 43 per cent, respectively.

As an example of a specific service within one

of the broad service classes described above, 90 per cent of eligible patients in the nursed group received ambulation assistance during the first 3 months of the study. The proportion remained at this high level during the first year and then decreased to 79 per cent by the end of the study. As another example of a specific service, 85 per cent received nursing services in relation to accident prevention at the beginning of the study.

In summary, study patients referred to the Visiting Nurse Association received continuing care at home. These patients actually received much more and extensive care than those not referred to the VNA, as measured by the number of people served, the number of visits per person, and the degree of sustained follow-up.

#### References

1. Reese, E.: Public Health Nursing and Comprehensive Health Care. *Nursing Outlook* 16: No. 1, 48-52, January 1968.

## CHAPTER V. INTERVIEWING AND MEASURES

Nurses, physicians, and sociologists were the research observers. They were trained and supervised by faculty with doctorate degrees and advanced academic and applied experience in biostatistics, internal medicine, preventive medicine, nursing, psychology, and sociology. In order to maintain the objectivity of observer evaluations, we did not give them details about the experiment's design nor about the process of random assignment of service and observation. We, furthermore, kept them geographically apart from service personnel to avoid communication and exchange of information.

### INTERVIEWING

Before the study began, we trained all observers in the interviewing procedures and gave them a guide which: 1) emphasized principles that applied to this particular study; (2) defined the content of the interview; (3) defined the observations and measures of the study; and (4) defined the sources of the definitions and measures. During the periods of observer training and data accumulation, the following principles were stressed and applied as consistently as possible (1).

The function of the observer was to establish and maintain contact with patients and families, to obtain accurate information without influencing patient behavior, and to record this information. In making first contact with the patient in the hospital, the observer introduced herself by name. She wore a white coat and, though she introduced herself as a member of the evaluating staff, she was occasionally identified by patients as a member of the hospital staff. She was attentive to questions about her role and carefully defined her position as nonservice. When the observer suspected that the patient had some concern or negativism, she

tried to get the patient to verbalize this before dealing with the problem. Explanations were then given in response to expressed questions, and anxieties related to unexpressed questions were avoided. In order to get assistance from the supervisory staff, the observer was given the option to delay her answers. At the end of each interview, she prepared the patient for the next interview.

During the interview, the observer used simple words which could be understood by the patient. The patient or informant was encouraged to talk freely and comfortably. The observer was attentive and ready to listen, constantly aware of her role as one who gathered information without influencing patient behavior. To this end, she did not give advice and avoided answering questions about care. She created a quiet, interested impression and was conscious of the impressions which might result from even such details as manner of dress. She conducted an interview that appeared unstructured, although she had a structured plan of interview content in mind, including also specific questions, observations, and data forms. She attempted to gain information in the course of natural conversation, a task which was made easier by the fact that the topics of research importance were of personal concern to the patient. The patient was, in fact, often inclined to expand on the topics and to continue the conversation.

The flow of conversation tended to follow a predictable pattern that the observer directed in subtle fashion, thereby gathering the required data. Neutral topics opened the interview, such as the weather, the observer's experience in finding her way to the patient's home, and objects of interest in the patient's home. The conversation was then directed to subjects of research importance, generally concerned with

observable physical activities of the patient as, for example, a discussion of the patient's walking status or of mechanical assistive devices in evidence. Such remarks led easily into a discussion of activities of daily living and the nature of assistance received by the patient. The topic of assistance was then followed by discussions of household composition, family structure, socialization, nature of medical care, and management of economic affairs.

As a check on accuracy and reliability of patient responses, the observer asked the patient to show her such things as: (1) the bathroom and (2) medications in another room or meaningful substitute objects. These requests created test situations for direct observation of transfer, locomotion, and communication. They served also as checks on the validity of information about going to toilet, transferring, and walking, and as indirect checks on the reliability of interview information about bathing and dressing, which require a degree of mobility. Observers were also able to form a judgment about general reliability and made other observational tests when indicated. It was frequently appropriate to ask the patient to demonstrate the location of the bathroom during that part of the interview in which bathing, dressing, and transfer were discussed. The physical activity served as a break in the conversation and gave the patient an opportunity to be active. In association with the term "bathroom", it was possible to discuss the more personal areas of research interest such as toileting and continence.

In the continuing conversation, such topics as "future plans of the patient" and "people interested in the patient" led to expanded discussion of household composition, family structure, social interaction, economic status, and nature of medical care. Since the observer tried to create the impression of an unstructured interview, the patient's conversation could easily digress from the schedule of questions. The observer continued to listen, keeping unanswered questions in mind some of which the patient answered in the course of this open-ended conversation. Many questions, thus, did not have to be asked. Rapport was

strengthened by the interested attitude of the observer, and the patient felt more at ease than would be possible under the circumstances of a stream of directed questions. Since it was necessary to influence the direction of the course of conversation, interviewers were instructed in methods of changing topics directly or indirectly and were provided with examples of guiding statements.

Whether information was obtained indirectly or by direct questioning, the interviewer was trained to be sensitive to its accuracy. She was aware that the patient was not familiar with research definitions of even such commonly used words as "bathing", "dressing", "friends", "employment", and "doctor". The interviewer, therefore, used the patient's own words and referred to objects and events that were familiar to the patient. The observer was instructed to check the accuracy of the patient's statements against other sources or by means of rephrasing questions. Many questions were often needed to confirm the accuracy of a claim of independent function, and confirmation often required additional observations. Patients were interviewed and observed wherever they lived. If the patient was unable to give information, a relative, friend, or attendant close to the patient was interviewed. Unless otherwise stated, the interval of evaluation was the 2-week period which immediately preceded the due date of the evaluation. Research forms were completed by the interviewer immediately upon leaving the patient.

#### *Frequency and Completeness of Interviews*

As described in the chapter entitled "The Research Plan", 150 patients were scheduled to have additional interviews one week after discharge from Abington House and every three months after intake into the study. This group was labeled "the observed group". The remaining 150 patients did not have the additional interval interviews and were termed "the non-observed group".

The process of carrying out interviews was under the control of the investigators, and, with infrequent exceptions, interviews were completed successfully according to schedule. We

Effects of Continued Care

present the number of interviews completed by experimental groups and by the eleven interview occasions in Tables 5.1 and 5.2. Each of the 150 patients in the observed group was scheduled for interviews on 11 separate occasions; intake, postdischarge, 8 interval interviews by the regularly assigned interviewer, and a terminal interview by the newly assigned terminal interviewer. Of the 1650 (11 x 150) scheduled interviews for the observed group, 78 per cent were completed: 17 per cent involved patients

who had died and were, thus, not eligible for interviews: 4 per cent were partially completed, and less than 1 per cent were not done. Each of the 150 patients in the non-observed group was scheduled for an intake interview and a terminal interview. Of the 300 (2 x 150) scheduled interviews for the non-observed group, 85 per cent were completed: 14 per cent involved patients who had died and were, thus, not eligible for interviews: and 1 per cent were not done or were partially completed.

Table 5.1—Completeness of Interviews for Observed Subgroups

Interview occasion	Observed and nursed subgroups (N+O+) <sup>1</sup>			Observed and non-nursed subgroups (N-O+) <sup>1</sup>		
	Interviews completed	Interviews not completed	Not eligible	Interviews completed	Interviews not completed	Not eligible
Intake	75	0	0	75	0	0
Postdischarge	75	0	0	75	0	0
3 mos.	69	1	5	70	0	5
6 mos.	66	0	9	64	3	8
9 mos.	61	1	13	59	4	12
12 mos.	57	2	16	59	3	13
15 mos.	54	3	18	56	5	14
18 mos.	51	4	20	51	8	16
21 mos.	48	4	23	51	6	18
24 mos.	44	6	25	42	12	21
Terminal	41	9	25	45	9	21
TOTALS	641	30	154	647	50	128

<sup>1</sup>“Interviews Not Completed” includes interviews partially completed and interviews not done. The column headed “Not Eligible” includes patients who had previously died and were, thus, not eligible for interviews. The symbols “N+O+” and “N-O+” refer to the experimental subgroups which had quarterly scheduled interviews as described in Chapter 2.

Table 5.2—Completeness of Interviews for Non-Observed Subgroups

Interview occasion	Non-observed and nursed subgroups (N+O-) <sup>1</sup>			Non-observed and non-nursed subgroups (N-O-) <sup>1</sup>		
	Interviews completed	Interviews not completed	Not eligible	Interviews completed	Interviews not completed	Not eligible
Intake	75	0	0	75	0	0
Terminal	50	2	23	54	3	18
Totals	125	2	23	129	3	18

<sup>1</sup>“Interviews Not Completed” includes interviews partially completed and interviews not done. The column headed “Not Eligible” includes patients who had previously died and were, thus, not eligible for interviews. The symbols “N+O-” and “N-O-” refer to the experimental subgroups which did not have quarterly scheduled interviews as described in Chapter 2.

## MEASURES

We collected information for the following research purposes: (1) to describe the study sample; (2) to check the comparability of treatment and control groups; (3) to measure and describe aspects of the medical and nursing care; (4) to study the effectiveness of treatment; and (5) to develop new knowledge about care and about methods for studying care. Physical, psychological, and social information about the patients was collected in terms of the measures which are summarized in Figure V-1. We describe the measures in condensed form here and refer the reader to the sources identified in Figure V-1 for more detailed definitions and methods. Chapter 13 of this report includes a time schedule of evaluations, reproductions of the forms on which information was recorded,

and, for certain measures, additional methodologic detail.

As they entered the study, we classified patients in terms of age, sex, marital status, education, occupation, Hollingshead's Two Factor Index of Social Class, household composition, types of persons who gave assistance, recent personal loss, and recent change in role—as well as in terms of physical, psychological, social, and economic function. In each instance, also, the hospital's medical staff determined the principal diagnosis leading to admission after a complete medical evaluation. As an index of the presence or absence of coexisting or associated chronic diseases, every patient was screened for abnormalities of electrocardiogram, blood sugar level, blood urea nitrogen level, cardiac sounds, blood pressure, weight, vision, use of digitalis, and use of insulin

Measures to characterize the population of chronically ill	Measures to identify changes in function of the chronically ill
Age Sex and race Primary diagnosis Coexisting disease (2) Activities of daily living (Index of ADL) (3) Walking (2) Range of movement and strength (4) House confinement  Marital status Occupation Education Social class (Hollingshead) (5) Census tract characteristics (6, 7, 8) Economic resources and productivity (9) Household composition Identity of people who assist Recent personal loss or change in role Social interaction frequency (adapted Townsend) (10)  Intellectual function (Raven test) (11) Memory and mental control (adapted Wechsler) (12) Scale of psychosocial adjustment (Highland View) (13)	Death Activities of daily living (Index of ADL) (3) Walking (2) Range of movement and strength (4) House confinement  Duration of noninstitutional living Hospitalization Admission to nursing home Economic dependence (adapted from Index of ISF) (9) Social interaction frequency (adapted Townsend) (10)  Intellectual function (Raven test) (11) Memory and mental control (adapted Wechsler) (12) Scale of psychosocial adjustment (Highland View) (13)

<sup>1</sup>Numbers correspond to references at end of chapter.

Figure V-1. Measures in Continued Care Study<sup>1</sup>

or one of the oral drugs for diabetes. A systematic review and record was made of the presence or absence of the following: chest pain for which a physician advised bed rest for two or more weeks; a history of a diagnosis of coronary attack or angina; cancer discovered within five years by documented record; and inflammatory or noninflammatory polyarthritis during the prior two months.

*Measures of Physical Function and Injury, and Measures at Death*

We used measures of patient function both to describe patients as they entered the study and as criteria of effectiveness of the treatment program. Measures of activities of daily living (ADL), walking, house-confinement, and range of movement and strength had been developed during 14 years of study in Abington House (2, 3, 4, 9, 14, 15).

We used the Index of Independence in Activities of Daily Living, an ordered 7-grade scale ranging from a high of *A* to a low of *G*, to rate functional performance in activities of daily living (3). Ratings according to this standardized composite measure were based on detailed evaluation by both history and observation of functional dependence in bathing, dressing, going to toilet, transferring, continence, and feeding. This index reflects the adequacy of a spectrum of organized neurological and locomotor responses and serves as a graded measure of such biological and psychosocial function. Walking was observed and classified according to the following 5-grade scale (2): walking by self, walking with mechanical assistance, walking with personal assistance, walking with mechanical and personal assistance, and not walking at all. We measured house-confinement in terms of the number of days on which the patient had been outside of his residence during the 2-week period which preceded the date of evaluation. Additional details about the definitions, procedures, and grading of activities of daily living, walking, and house-confinement are described in Chapter 13.

A standardized test of range of movement and strength was used to define the severity of neuromuscular disability (4). In this test, we

asked the patient to perform a series of six maneuvers with each lower limb and 10 maneuvers with each upper limb. All maneuvers were tested both with and without resistance. Maneuvers were tested using defined positions for evaluating movement, defined points for applying resistance, defined avoidance of substitute maneuvers, and standardized definitions of range of movement in degrees. We classified function according to this test into four grades of function for each lower limb and three grades for each upper limb. Additional details about the test procedures and grading process are described in Chapter 13, which includes also the test form.

Whenever a patient fractured a bone during the study, we recorded the date and type of fracture. The occurrence of fracture served as a measure of injury.

When a study patient died, the following information was copied directly from the death certificate; date of death, birthdate, immediate cause of death, clinical code of cause of death, underlying cause of death, significant contributing conditions, presence or absence of autopsy, place of death (hospital or not), and attendance by a physician on the date of death. We made no effort to reconstruct the patient's functional status immediately before death because such information could not be reliably compared with measurements made at planned intervals. For deceased patients who had been observed quarterly, we had complete information through the last actual interview before death. For those who had not been observed regularly, interval functional evaluations were not available.

Some kinds of objective information could be verified and were obtained for all who died. These data included date of retirement or cessation of homemaking; dates of admission to and discharge from hospitals, nursing homes or other institutions; whether or not the subject was cared for at home by a nurse during the study; and dates of any fractures.

*Social and Economic Measures*

We recorded social factors in three categories: (1) socioeconomic status and function, (2) social interaction, and (3) social deprivation.

Socioeconomic class was measured first by Hollingshead's Two Factor Index of Social Position, which is based on education and occupation (5). In addition, we used a second measure which was designated as the Index of Economic Dependence and which had been derived from earlier studies on similar groups of patients (9). Based on detailed evaluations of indicators of resources and productivity, this measure consists of four classes in order of increasing economic dependence, derived from information about employment status, home ownership, and receipt of economic assistance from a charitable agency. Additional details about the grading process are described in Chapter 13, which includes also the form used to record information.

As a measure of social role, we classified patients according to whether or not they had been working or acting as homemakers until the onset of the illness which led to hospitalization. Dates of cessation were recorded if patients were no longer employed or homemaking. Household composition was identified as one of eight categories: married pair living with children; married pair living with others; married pair living alone; solo (i.e., single, separated, widowed, or divorced) living with children; solo living with other relatives; solo living with non-relatives; solo living alone; and not in a household (usually meaning in a nursing home). For analysis and as a more clearly graded measure of household composition, we condensed these eight categories into three: married and living with spouse, solo living with others, and living alone.

Utilizing certain ideas of Townsend, we defined a measure of personal interaction based on the number of kinds of persons with whom the subject reported having daily contact (10). The kinds of persons were classified as spouse, relatives, or friends; and each individual was identified as having daily contact with 3, 2, 1, or none of these categories. As other measures of social activity, we sought the following information: the number of people talked to daily, whether the subject had been employed during the two weeks before hospitalization, and whether the subject had engaged in any regular

organized social activity such as church or club activities.

We defined social deprivation as one or more of the following events in the two years before the subject entered the study: loss of spouse, retirement, or cessation of homemaking (16). An additional measure possibly related to these three, was whether or not the individual reported that he talked to fewer persons at the time the study began than he had at age 45. Institutionalization was recorded in terms of dates of entry into hospitals and nursing homes, and the corresponding dates of discharge.

#### *Psychological Measures*

Tests of mental and psychosocial function included the Raven Coloured Progressive Matrices, a standardized memory and mental control scale adapted from Wechsler, and a Q-sort method for evaluating psychosocial adjustment (11, 12, 13). The Raven Coloured Progressive Matrices is a standardized measure of observation and clear thinking which has been used for the elderly and which has been found to correlate reasonably well with the Wechsler Adult Intelligence Scale (11, 17, 18). This test consists of three sets of twelve untimed multiple choice problems, each set being arranged in order of progressive difficulty. Each problem consists of a matrix design from which a segment has been removed plus six possible inserts from which the subject selects the one correct, matching insert. Requiring no manual dexterity and no spoken language, it is suitable for administration to children, the aged, and the disabled; and its spectrum of intellectual difficulty is appropriate for these groups.

We evaluated orientation and mental control with the aid of an instrument which was adapted from the Wechsler memory scale (12). This scale taps the basic mental status of the subject, testing for orientation for time, place, and person, as well as for simple mental control. The orientation sections include questions about the year, the month, the day, the subject's physical location, name, age, and marital status. Evaluation of mental control is based on the subject's ability to recite the alphabet, count backwards, and count by threes.

Interviewers rated the psychosocial adjustment of patients by a Q-sort technique which had been developed at Highland View Hospital (13). By this method, interviewers rated 4 dimensions of behavior in each of 3 areas, namely, motivation, social adjustment, and personal adjustment. Each descriptive statement of the rating continuum of each dimension of behavior was printed on a card. To rate a given patient, all cards were arranged in order, one end of the ordered series being those behavioral characteristics which were most unlike the patient and the other end being those most like the patient. Details about Q-sort items, forms, and scoring are found in Chapter 13.

#### Measures of Care

Interviewers recorded information about care in terms of hospitalizations and nursing home utilization, as well as in terms of physician, nurse, and other professional services. Dates of entering and leaving hospitals and nursing homes were listed and verified by checking against hospitalization insurance records and, systematically, with the institutions themselves. Numbers of contacts with physicians and nurses were recorded on the basis of questions adapted from the U. S. National Health Survey (19). Counts were also made of services by dentists, optometrists, podiatrists, social workers, and physical therapists. Nurses of the Visiting Nurse Association kept records of their services in relation to exercises, prescribed treatments, activities of daily living, health promotion, planning, coordination, and psychological therapy. Systematic records of these services were returned to the research offices each month.

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## CHAPTER VI. CLASSIFICATION OF DISEASE, DISABILITY AND MENTAL STATUS AT INTAKE

The subjects of this study had moderate to severe physical disability. A few showed mental confusion, and all had been admitted to the hospital at one stage or another of various chronic diseases (Chapter 3). Each of these characteristics, alone or in combination with others, was likely to exert its particular influence on the course to be expected, and on the person's capacity to respond to the nursing program. The number of characteristics and combinations was large; thus, the population was quite heterogeneous in terms of disease, disability, and mental status. Since heterogeneity is associated with increased variability which could obscure many effects of the treatment program, we found it necessary to establish subgroups of individuals who were comparable at the time they entered the study. This chapter describes the systems of classification which we used to establish comparable subgroups for disease, disability, and mental status; and the next chapter (Chapter 7) deals with the treatment program's effects in terms of these classification systems. Classes were defined before results were analyzed in order to avoid the biases of retrospective classification.

Our approach to classification had been developed during a period of about 13 years through epidemiological and experimental studies of chronically ill patients. The following discussion is based on the experiences in these past studies and serves as important background information with respect to the approach to classification which we took in the present study.

Information which can be used to classify disease, disability, and mental status can be obtained from the customary procedures of

clinical medicine or from systematic application of predefined criteria by means of questions, observations, or tests. Classes can, thereby, be defined in such terms as clinical diagnosis or as signs or indicators of disease or disability. Use of terms of clinical diagnosis as criteria for classifying patients is illustrated by the International Classification of Diseases, which is based on a mixture of anatomic, clinical, etiologic, pathologic, and physiologic criteria (1). Use of indicators of disease and disability to classify population groups is illustrated in reports concerning the prevalence of disease and disability by the National Health Survey and Commission on Chronic Illness (2, 3, 4). Each type of information has advantages and disadvantages, and neither is adequate by itself to define groups of persons with comparable prognoses or to establish groups which are ordered according to severity of illness.

Diagnosis is a common basis for classification and is the usual starting point in defining patients' needs for care and in organizing services. Problems encountered with existing systems of diagnostic classification relate to difficulties in establishing specific diagnoses, difficulties in defining the stage and severity of chronic illness, and the great variability of chronic disease characteristics. With respect to diagnosis, we lack the means to identify with certainty the existence and stage of many chronic diseases as, for example, in certain early stages of hypertensive cardiovascular disease, arteriosclerotic heart disease, cancer, or mental disorder (5, 6, 7, 8, 9). In the absence of knowledge about cause, diagnostic procedures are not completely definitive; and we miss numerous instances of early and mild illness. Classification of patients according to clinical

diagnosis does not, therefore, include all those who have a specific disease. Attempts to search for the presence or absence of all diagnoses are impractical, and certain diagnostic procedures involve risks to patients. Because of variations in skill, information, and criteria, the use of diagnostic categories alone to describe large populations is likely to result in long lists with many small subgroups and much overlapping. Associated with incomplete knowledge about causes of disease and pathogenesis is a dearth of quantitative information about the natural progression and regression of chronic disease (10). As a result, knowledge about milestones of disease is poorly developed; and existing systems of diagnostic classification are of little value to describe changes in the stages and severity of illness. Finally, current systems of classification do not adequately take into account the marked variation in patterns of chronic disease in terms of the kinds, numbers, severity, and complications of disease. Two patients, both with the diagnosis of stroke, for example, may differ greatly in the amount of measurable disability they present. On the other hand, two patients with the same degree of disability may have quite different prognoses if the disability is the result of different disease conditions. In a study such as the present one, a system of classification which does not recognize variation in disease patterns is likely to obscure study results.

In contrast to diagnostic classification, the use of signs or indicators permits systematic characterization of population groups in standard terms and saves time and cost. (Nonsystematic diagnostic review, no matter how thorough, does not result in comparable classes). Despite such advantages, however, the use of indicators for classification has distinct limitations. Indicators are selected on the basis of their validity as indicators of disease. Since our current knowledge about causes and dynamics of chronic disease is generally incomplete, indicators do not establish with certainty whether the respective conditions are present or absent. For example, the sensitivity and specificity of indicators are unknown with

respect to most chronic diseases. As a result, the occurrence of false positives and false negatives could obscure interpretations about findings in a study such as ours. In this type of study, also, only indicators of fairly prevalent conditions can be used.

Classification of patients according to disability has certain advantages over classification according to clinical diagnoses or indicators of disease. As a criterion which can be measured objectively, disability is an index of the existence, stage, and effects of chronic disease at a time when information about etiology and pathogenesis is not complete enough to permit measurement in more basic terms. Degree of disability is, thus, one index of severity of illness and a sensitive indicator of changes in the course of illness. An important advantage offered by measures of disability and function is that they provide a conceptual basis for homogeneous groupings in diagnostically heterogeneous populations. Examples of the use of disability classifications as measures of morbidity are found in reports of the Commission on Chronic Illness and National Health Survey, which describe the prevalence of various types of disability in large populations (2, 3, 11). In the present study, we have made use of a measure of disability, the Index of Independence in Activities of Daily Living, which we developed in extensive studies of similar patients (12, 13). Its reliability and validity have been studied, and it has been shown to differentiate groups of patients with different prognoses and to be related to patterns of physical and behavioral development (12, 13, 14, 15).

In view of the previously discussed problems and concepts, we established three systems of classification from combinations of three types of information in order to study the effects of the treatment program in comparable subgroups of individuals. The three types of information were, principal clinical diagnosis, indicators of chronic conditions, and degree of disability. Each type of information served as the basis for a system of classification, and the three systems will be described below. The classifications were based on previous experiences in studies of the natural history of stroke, fracture of the hip,

and Parkinson's disease (14, 15, 16); and they had also been used successfully in a controlled study of comprehensive care for outpatients with rheumatoid arthritis (17). An important criterion in selecting classes was to have them contain sufficient numbers of subjects to permit meaningful analysis.

#### *Classes Based on Principal Clinical Diagnosis*

For the first system of classification, we grouped patients according to principal diagnosis, defined as the diagnosis which led to the hospital admission (Chapter 3). We divided each diagnostic class into two subcategories, one containing those who had the specific diagnosis plus one or more indicators of coexisting major chronic conditions (cardiovascular-renal disease, cancer, severe disability, or dementia), and the other containing persons with the same diagnosis but without these indicators of chronic conditions. Since the indicators were measured in similar terms for all subjects, the subdivided classes were more homogeneous than groups of patients classified according to principal diagnosis alone.

Stroke and fracture of the femur were the two diagnostic categories which contained the largest numbers of individuals, while other single disease classes were not large enough for analysis. By including closely related diagnoses, we defined enlarged diagnostic classes and subdivided them according to the presence or absence of indicators of coexisting major chronic conditions. The combined categories included brain disease, muscular and skeletal conditions, and cardiovascular-renal disease. We established a total of fourteen classes as defined in Table 6.1, which also defines the indicators of coexisting major chronic conditions (Intake Classes #28 through #42 in Chapter 14). Excluded from Table 6.1 are the classes which were not large enough for analysis, either as single diseases or as combined categories.

#### *Classes According to Disease-Disability Profiles*

The second type of classification grouped patients according to profiles of disease and

Table 6.1—Classes Based on Principal Diagnosis and Coexisting Major Chronic Conditions

Principal Diagnosis	Coexisting condition <sup>1</sup>	No. of persons
Stroke	Present	60
Stroke	Absent	15
Stroke or chronic brain syndrome	Present	76
Stroke or chronic brain syndrome	Absent	18
Any brain condition <sup>2</sup>	Present	90
Any brain condition	Absent	21
Fraction of femur	Present	34
Fraction of femur	Absent	2 <sup>3</sup>
Fracture of lower limb <sup>3</sup>	Present	41
Fracture of lower limb	Absent	28
Any muscular or skeletal condition <sup>4</sup>	Present	57
Any muscular or skeletal condition	Absent	53
Cardiovascular-renal disease <sup>5</sup>	Present	77
Cardiovascular-renal disease	Absent	24

<sup>1</sup>Coexisting chronic conditions are one or more of: 1) cardiovascular-renal disease (abnormal Q-wave on EKG, or blood urea nitrogen of 30 mg. or more per 100 ml.), 2) cancer occurring within 5 years, 3) severe general disability (Index of ADL grade of F or G), or 4) dementia (Raven test score of 12 or less, or orientation test score of 13 or less).

<sup>2</sup>Stroke, chronic brain syndrome, paralysis agitans, multiple sclerosis, subarachnoid hemorrhage, subdural hematoma, cerebral contusion, idiopathic cerebellar atrophy, idiopathic progressive paresis, basilar artery insufficiency, or apraxia.

<sup>3</sup>Fractures of femur, femoral condyle, tibia, fibula, ankle, or metatarsals. A patient with partial ankylosis of the knee after fracture and with posttraumatic subluxations of metatarsals were also included.

<sup>4</sup>Fractures of the lower limb (defined above), osteoarthritis, rheumatoid arthritis, idiopathic myopathy, gout, chondrocalcinosis, ligamentous strain of hip, fractured clavicle, fractured humerus, Colles' fracture, fractured wrist, osteoporotic compression fractures of vertebrae, fractured pelvis, aseptic necrosis of head of femur, and atrophy after poliomyelitis with post fracture nonunion and amputation.

<sup>5</sup>Arteriosclerotic heart disease (including myocardial infarction), stroke, generalized arteriosclerosis, hypertensive cardiovascular disease, rheumatic heart disease, basilar artery insufficiency, anterior spinal artery syndrome, and amputations for occlusive vascular disease.

disability, based on an idea developed by members of the Commission of Chronic Illness (11). By this system, persons in the Commission's study of chronic illness were divided into three classes. The first class included those with maximum disability regardless of diagnosis. The second and third classes had less disability, the second class having some disease and the third having no or minor disease. The three disease-disability classes were, thus, ordered according to severity and reflected the burden of illness in those who were evaluated.

In the present study, we divided all 300 patients into three classes according to the above concept. Those with maximum disability (having an Index of ADL grade of *F* or *G*) were included in the first class regardless of diagnosis (Intake Class #2 in Chapter 14). Patients in the second and third classes had less disability. Those in the second class had at least one indicator of coexisting major chronic conditions (Intake Class #3 in Chapter 14), while those in the third class had no such indicators (Intake Class #4 in Chapter 14). The use of indicators, instead of diagnoses as used in the Commission studies, took advantage of the better reliability of systematically tested disease indicators. The coexisting chronic conditions for the second class were cancer (documented occurrence within 5 years), coronary disease (abnormal Q-waves on EKG), and renal disease (blood urea nitrogen level of 30 mg. or more per 100 ml.).

We evaluated the effect of varying definitions for the second class by adding one or more of the following indicators: hypertension, maintenance therapy with digitalis, and proteinuria. Based on such modified definitions, we established four other sets of classes, the respective four sets being Intake Classes #2, #5, #6, #7, #8; #2, #9, #10; and #2, #11, #12. Patients were distributed approximately in thirds between the classes of each set, no class having fewer than 74 or more than 133 patients.

#### *Classes Based on Indicators of Major Chronic Conditions*

The final type of classification grouped patients according to patterns of four major chronic conditions, namely, cardiovascular-renal disease,

cancer, severe disability, and dementia (Intake Classes #13 through #27 in Chapter 14). The first two conditions (cardiovascular-renal disease and cancer) identify the leading causes of death in the United States today, while the latter conditions (disability and dementia) reflect physical and mental morbidity which is most serious for the particular patients in this study. By the term "dementia", we mean "any condition of deteriorated mentality" which is roughly synonymous with the common term "senility" or the clinical diagnosis of chronic brain syndrome (18).

By systematic evaluation, we established whether the previously defined indicators of these conditions were present or absent, and we produced comparable information for all patients (Tables 3.2, 3.3, and 3.6). Cutoff points with respect to these indicators were defined in relation to their relevance to the people and purposes of this particular study. To the degree that knowledge is limited, we recognize that judgments differ about cutoff levels and definitions. The conceptual bases and definitions in this study are, however, presented clearly and will permit the reader to visualize the basis for interpretation of study results and the people to whom such results apply.

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## CHAPTER VII. EFFECTS OF TREATMENT PROGRAM: ALL PATIENTS AND SUBGROUPS BY DISEASE, DISABILITY AND MENTAL STATUS

In the preceding chapter, we described a system of disease and disability classification which had been developed to define homogeneous subgroups of patients. The concepts and experiences on which the syntheses were based were also described in detail. The present chapter reports significant associations between the treatment program and the outcome for subgroups of patients which were homogeneous for *principal clinical diagnosis*: (with and without coexisting chronic conditions), *disease-disability profiles*, and *indicators of major chronic conditions* (cardiovascular-renal disease, cancer, severe disability, and dementia). The first section of the chapter deals with effects of the nursing program in terms of function (physical, mental, and social), injury, and mortality. The second section discusses outcome in terms of use of services.

### *Areas of Measurement*

Our primary interest in the study was in the effectiveness of the treatment program in maintaining or improving physical, psychological, and social well-being of the patients (measured in terms of function). Certain kinds of interpretations about patient well-being are, of course, more acceptable than others, due to limitations of available measures. For some functions, for example, such as walking and activities of daily living, we have precisely defined reproducible measures, while for other functions, such as social interaction and social adjustment, definitions and reproducibility of the measures are limited. Another limitation is that currently available measures do not cover all the areas of function included in the concept of comprehensive human well-being.

Our second interest in the study was in the influence of the treatment program on patients'

use of medical and other services. To the extent that use of services indicates that patients are receiving the benefit of the skills and experiences which are part of the professional's background, such use is an indicator of quality care. One must bear in mind, however, that this consideration is theoretic; and the actual effect on patient well-being is not necessarily proved by demonstrating increased use of services alone. At the same time, the possibility exists that, for patients who are chronically ill, use of services reflects the public health nurse's coordinator function and is definitely related to the patients' welfare.

In presenting the results of the study, we shall represent both of the areas of interest mentioned above. We shall describe the first area under the heading *Function, Injury, and Mortality*, and the second under the heading *Use of Services*. Function was evaluated in terms of activities of daily living, walking, range of movement and strength, orientation and mental control, observation and clear thinking, degree of house confinement, socioeconomic function, and social interaction, while the occurrence of injury was evaluated in terms of the occurrence of fractures (Outcome Classes #3 through #17 in Chapter 14). We evaluated use of services by patients in the study in terms of hospitalizations, admissions to nursing homes, nurse visits, physician visits, services by other professionals and nonprofessionals, and service circumstances at the time of death, including attendance by a physician on the day of death, death in hospital, and autopsy (Outcome Classes #18 through #28 in Chapter 14).

For the analyses in both this chapter and Chapter 9, definitions of change in physical, mental, and social function excluded death as an item of change. In relation to physical and

mental function, a "beneficial" treatment effect was defined as improvement or maintenance (not improvement alone), since the study's main hypothesis was that function would be improved or maintained in the presence of the experimental care variable. We did not, however, use the terms "benefit" or "improvement" to describe social effects, since changes in social functions as, for example, participation in social activities, cannot be clearly interpreted as changes for the better or worse in this disabled and aging population. Such changes in social function are less clearly measures of well-being than are changes in physical and mental function. The same is true for changes in house-confinement which may be influenced as much by social and psychological factors as by physical disability. We, therefore, described changes in social function and house-confinement as increases or decreases; and interpretation of the meaning of such increases or decreases are explored in Chapter 11, where we discuss implication of the study results. Lastly, in both this chapter and in Chapter 9, such phrases as "more often associated", "occurred more frequently", "more frequently maintained or improved", "fewer deteriorations", "beneficial nursing effect", "more services" and "fewer admissions" are all based on demonstrated significance by statistical test and on the principles of statistical inference which are described in Chapter 12.

#### *Outcome in Terms of Function, Injury, and Mortality*

Differences in function, injury, and mortality were not demonstrated between the study groups which included all patients, namely, between the heterogeneous nursed and non-nursed groups.

Among certain subgroups which were homogeneous for disease and disability, statistically significant and consistent differences were demonstrated between nursed and non-nursed groups. The most frequent outcomes in the presence of the nursing program were: (a) beneficial nursing effects in physical and/or mental function among patients who had a principal diagnosis of a muscular or skeletal condition without a coexisting major chronic condition, those who had a principal diagnosis of arthritis, those who were least severely ill, and those with less than maximum disability;

and (b) decreased social interaction for a few subgroups which had, in common, poor mental function and cardiovascular-renal abnormalities.

By statistical test, we did not demonstrate differences in function, injury, and mortality between the study groups which included all patients, namely, between the heterogeneous nursed and non-nursed groups. This was true for analyses of differences in activities of daily living, walking, range of movement and strength, orientation and mental control, observation and clear thinking, socioeconomic function, social interaction, degree of house-confinement, occurrence of fractures during the study, and mortality.

Among subgroups which were homogeneous for disease, disability, and mental status, we demonstrated statistically significant differences which revealed associations between the treatment program and the study's outcome. These associations in homogeneous subgroups will be described next, and we refer the reader to Chapter 6 for more detailed definitions of the classes of disease, disability, and mental function.

Considered, first, are outcomes for patients classified according to *principal diagnosis* as they entered the study. For patients who had a principal diagnosis of a muscular or skeletal condition without a coexisting major chronic condition (indicators of cardiovascular-renal disease, cancer, severe disability, or dementia), the presence of the nursing program was associated with a beneficial outcome. The types of beneficial outcome included fewer deteriorations by measures of walking, range of motion, and orientation and mental control (Table 7.1).

We did not demonstrate differences in the previously listed outcome measures of function, injury, and mortality between nursed and non-nursed subgroups of patients who had a principal diagnosis of fractured femur or another fracture of the lower limb, whether such groups included those with (41 patients) or without (28 patients) a coexisting major chronic condition. It should be noted, however, that the experimental subgroups in these instances were small. Patients who had a fracture of the femur or another lower limb fracture comprised almost

Table 7.1—Nursing Effect on Deterioration in Function Two Years After Study Intake in Patients Who Had Principal Diagnoses of Muscular or Skeletal Conditions

	Patients who had muscular or skeletal conditions <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not referred to Visiting Nurse (N-)	
Walking			
Deterioration <sup>2</sup>	0	7	7
No deterioration	16	20	36
Range of Movement			
Deterioration <sup>2</sup>	1	11	12
No deterioration	15	16	31
Orientation and Mental Control			
Deterioration <sup>2</sup>	1	10	11
No deterioration	15	14	29

<sup>1</sup>Patients include those who had principal diagnoses of muscular or skeletal conditions without coexisting major chronic conditions as defined in Table 6.4 of Chapter 6.

<sup>2</sup>Deterioration in walking is Outcome Class #4 defined in Chapter 14. Deterioration in range of movement is Outcome Class #9. Deterioration in orientation and mental control is Outcome Class #11. Differences in totals reflect variations in the numbers of patients for whom identification of deterioration was possible.

two-thirds of those who had a principal diagnosis of a muscular or skeletal condition (69 of 110 patients). About three-fourths of the remaining patients who had muscular and skeletal conditions had a principal diagnosis of arthritis; and Table 7.2 presents evidence of the beneficial effects of the nursing program on the outcome in patients with arthritis in terms of fewer deteriorations in range of movement.

We did not demonstrate differences in any of the 16 outcome measures of function, injury, and mortality between nursed and non-nursed subgroups of patients who had a principal diagnosis of stroke. This was true for those who had stroke with or without a coexisting major chronic condition. Similarly, no difference was observed between nursed and non-nursed subgroups of patients classified according to combined categories of central nervous system diagnoses, namely, stroke or chronic brain syndrome, any brain condition, and cardiovascular-renal disease (including vascular disease of brain or spinal cord).

We, next, considered outcome in patients classified according to *disease-disability profiles* which were ordered according to severity. Experimental subgroups with maximum disability (assisted in bathing, dressing, toileting, and transferring, in addition to being incontinent and/or receiving assistance in feeding) did not differ in outcome by any of the measures of function, injury, and mortality. Experimental subgroups with less than the preceding degree of maximum disability did show differences in outcome, and such differences were limited to outcome in physical function (Figure VII-1). Among patients with less than maximum disability and with coexisting major chronic conditions, the subgroup assigned to the nursing program had fewer deteriorations by the range of movement test. In this class of patients, 1 deteriorated among 38 assigned to the nursing program, and 7 deteriorated among 41 not so assigned. This beneficial nursing effect was evident for those having one or more of the following abnormalities: cancer present in the

Table 7.2—Nursing Effect on Deterioration in Range of Movement  
Two Years After Study Intake in Patients Who Had Arthritis

	Patients Who Had Arthritis <sup>1</sup>		
	Referred to Visiting Nurse (N+)	Not referred to Visiting Nurse (N-)	Totals
Range of Movement Deterioration <sup>2</sup>	2	11	13
No deterioration	9	6	15

<sup>1</sup>Patients include those who had principal diagnoses of rheumatoid arthritis, osteoarthritis, gout, or pseudogout.

<sup>2</sup>Deterioration in range of movement is Outcome Class #9 defined in Chapter 14.

past five years, abnormal Q-waves on the electrocardiogram, azotemia, or taking a cardiac glycoside regularly. When we modified the classification of major abnormalities by including various combinations of other cardiovascular-renal criteria (hypertension and proteinuria), we did not demonstrate differences in outcome between the experimental subgroups.

Experimental subgroups with the least severe of the three disease-disability patterns, namely, those without maximum disability and without coexisting major chronic conditions, also differed in outcome. Walking and range of movement were more frequently maintained or improved in the nursed group than in the non-nursed group. The respective ratios in the nursed and non-nursed groups were 35 of 38 patients and 31 of 41 for walking, and the respective ratios were 34 of 38 and 31 of 43 for range of movement.

Outcome was also studied in patients classified according to *disability* status in terms of activities of daily living and in the large number (222 patients) with indicators of major *cardiovascular-renal* disease. In these studies, we also evaluated outcome with respect to adequate or poor *mental function*. Patients in the less dependent classes of activities of daily living (grades A, B, C, or D by the Index of ADL) more often improved or maintained both range of movement and orientation and mental control in the presence of the nursing program than in its absence (Table 7.3). When patients in these less dependent classes of activities of daily living

were subdivided according to the presence of adequate or poor mental function, the same beneficial nursing effect was demonstrated for those with good mental function, while no such effect was demonstrated for those with poor mental function. After demonstrating beneficial nursing effects among those who had lesser degrees of disability in activities of daily living, we evaluated effects among patients classified in other disability terms. The least disabled patients consistently benefited the most. Confirmatory evidence included fewer deteriorations in range of movement among those who were less limited in range of movement at intake and fewer deteriorations in orientation and mental control among those who were able to walk without assistance at intake. The outcome studies in disability and cardiovascular-renal subgroups did not, otherwise, add to or change interpretations made in the outcome studies based on other classification systems of disease and disability described in this chapter.

Finally, for patients in certain disease classes, a type of social outcome which was more frequent in the nursed group than in the non-nursed group was the outcome which reflected decreased social interaction and which was defined as "fewer social activities at the terminal point than at intake". Included were 4 classes, 3 of which had, in common, poor mental function and 2 of which had evidence of cardiovascular-renal disease. The remaining disease and disability classes were not associated with differences in function, injury, or mortality

Severity of illness grades <sup>2</sup>	Nursing effect on individual functions <sup>1</sup>				
	Walking	Activities of daily living	Range of movement		
			Upper limb	Lower limb	Any limb
Most severe	0 <sup>3</sup>	0 <sup>3</sup>	0 <sup>3</sup>	0 <sup>3</sup>	0 <sup>3</sup>
Moderately severe	0 <sup>3</sup>	0 <sup>3</sup>	0 <sup>3</sup>	0 <sup>3</sup>	Beneficial effect
Least severe	Beneficial effect	0 <sup>3</sup>	Beneficial effect	0 <sup>3</sup>	Beneficial effect

<sup>1</sup> Individual functions are defined in Chapter 5, and the measures of effects are the changes in function expressed as Outcome Classes #3, #4, #7, #8, and #9 in Chapter 14. The nursing effect was defined as "beneficial" when function was maintained or improved more frequently in the presence of the nursing program than in its absence (by statistical test)

<sup>2</sup> Severity of illness grades are defined in Chapter 6 according to disease-disability profiles and are specified as Intake Classes #2 through #12 in Chapter 14. Patients in Intake Class #2 were the most severely ill. Those with illness of moderate severity were in any of Intake Classes #3, #5, #7, #9, or #11; and the least severely ill were in any of the Intake Classes #4, #6, #8, #10, or #12.

<sup>3</sup> 0 = no beneficial or adverse effect demonstrated.

Figure VII-1. Treatment Effect on Physical Function According to Severity of Illness

Table 7.3—Nursing Effect on Deterioration in Function Two Years After Study Intake in Patients Graded A, B, C, or D by the Index of ADL

	Patients Graded A, B, C, or D by Index of ADL <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not referred to Visiting Nurse (N-)	
Range of Movement Deterioration <sup>2</sup>	1	10	11
No deterioration	26	25	51
Orientation and Mental Control Deterioration <sup>2</sup>	6	16	22
No deterioration	20	16	36

<sup>1</sup>See Chapter 5 for detailed definitions of the Index of ADL. By the Index, patients graded as A, B, C, or D are more independent in activities of daily living than those graded as E, F, or G.

<sup>2</sup>Deterioration in range of movement is Outcome Class #9 defined in Chapter 14. Deterioration in orientation and mental control is Outcome Class #11. The difference in totals reflects the difference in numbers of patients for whom identification of deterioration was possible.

in terms of these or any of the other measures of physical, psychological, or social outcome between the nursed and non-nursed subgroups.

#### *Outcome in Terms of Use of Services*

Aside from the expected difference of more visiting nurse visits in the experimental group which was designed to receive such visits, more patients in the nursed group were admitted to hospitals during the study than in the non-nursed group; and autopsies were performed more frequently on those in the nursed group who died.

Among subgroups which were more homogeneous for disease and disability at the time of entry into the study, the most frequent outcomes in the presence of the nursing program were: (a) more patients hospitalized among those who had a principal diagnosis of fracture of the femur plus a coexisting major chronic condition, those who were most disabled, and those with less than maximum disability who were also free of major chronic conditions; (b) more contacts with physicians among those who had a principal diagnosis of stroke plus a coexisting major chronic condition, those who had a principal diagnosis of cardiovascular-renal disease plus a coexisting major chronic condition, and those who were most disabled; (c) more non-nurse and non-physician services among those who were most disabled and among those with less than maximum disability who were also free of major chronic conditions; (d) fewer

admissions to nursing homes among patients who were not maximally disabled in activities of daily living at the time of entry into the study; and (e) more hospital services at the time of death among those who had a principal diagnosis of cardiovascular-renal disease plus a coexisting major chronic condition and those who were most disabled.

Concerning the use of services by patients in the study, we demonstrated differences between the study groups which included all patients. Aside from the expected difference of more visiting nurse visits in the experimental group which was designed to receive such service, more patients in the nursed group (95 of 141 patients) were admitted to the hospital during the study than in the non-nursed group (76 of 137 patients). The frequency of hospitalizations is described in Table 7.4. Autopsies were, also, more frequently performed on deceased patients in the nursing program than on those not in the nursing program.

We devote the rest of this section to outcome in homogeneous subgroups of the nursed and non-nursed groups. We shall, first, discuss outcome in subgroups which were homogeneous with respect to *principal diagnosis* of patients. More patients in the nursed group who had a fracture of the femur plus a coexisting major

Table 7.4—Nursing Effect on Frequency of Hospitalizations During the Study

Number of Hospitalizations	Experimental Groups	
	Referred to Visiting Nurse (N+)	Not referred to Visiting Nurse (N-)
	(number of persons)	
0	55	74
1	51	37
2	28	22
3 or more	16	17
TOTALS	150	150

chronic condition were hospitalized than were similar patients in the non-nursed group (12 of 16 in the nursed group as compared to 4 of 15 in the non-nursed group). As related and consistent findings, more of those with principal diagnoses of any lower limb fracture plus major comorbidity and more with principal diagnoses of muscular or skeletal condition plus major comorbidity were hospitalized in the presence of the nursing program (14 of 21 with any lower limb fracture and 19 of 28 with a muscular or skeletal condition) than in its absence (5 of 17 with any lower limb fracture and 10 of 25 with a muscular or skeletal condition). The reader should note that, of the 53 with principal diagnoses of muscular or skeletal condition plus major comorbidity, 31 had a principal diagnosis of fracture of the femur, and 7 had other fractures of the lower limb.

No difference in the number hospitalized was demonstrated between nursed and non-nursed subgroups of patients who had a muscular or skeletal condition without a coexisting major chronic condition, nor between those who had a fractured femur without such comorbidity or any lower limb fracture without comorbidity. We did not demonstrate difference in physician contacts between nursed and non-nursed patients who had a muscular or skeletal condition with or without a coexisting major chronic condition. Similarly, differences in physician contacts were, similarly, not demonstrated for

those who had a fractured femur or any lower limb fracture with or without major comorbidity.

Patients in the nursed group who had a principal diagnosis of stroke plus a coexisting major chronic condition had more contacts with physicians during the two weeks before their terminal interview (15 of 24) than did similar non-nursed patients (4 of 17). Related and consistent findings were more contacts with physicians for patients who had stroke or chronic brain syndrome plus major comorbidity and for patients who had any brain condition plus major comorbidity in the presence of the nursing program (15 of 28 with stroke or chronic brain syndrome and 17 of 31 with any brain condition) than in its absence (5 of 20 with stroke or chronic brain syndrome and 7 of 25 with any brain condition).

In comparing nursed and non-nursed subgroups, we did not demonstrate differences between the numbers admitted into hospitals for the following classes of principal diagnoses (with or without major comorbidity): stroke, stroke or chronic brain syndrome, and any brain condition. Contacts with physicians did not differ among patients in the following classes: stroke without a coexisting major chronic condition, stroke or chronic brain syndrome without a coexisting major chronic condition, and any brain condition without a coexisting major chronic condition.

Nursed patients with a principal diagnosis of cardiovascular-renal disease plus a coexisting major chronic condition had more frequent contacts with physicians during the two weeks before their terminal interview (19 of 30 patients) than did corresponding patients in the non-nursed group (4 of 20 patients). The same diagnostic class had more in-hospital deaths in the nursed group (11 of 16 who died) than in the non-nursed group (2 of 11 who died). No differences in the numbers of patients hospitalized were demonstrated between nursed and non-nursed patients who had cardiovascular-renal disease with or without major comorbidity, and no difference was demonstrated with respect to contacts with physicians for

those who had cardiovascular-renal disease without major comorbidity.

Next, we consider outcome with respect to *disease-disability profiles*. Among patients classified according to the total burden of illness in terms of disease-disability profiles which were described in Chapter 6, more of those with maximum disability were hospitalized in the presence of the nursing program than in its absence. Here, 30 of 41 nursed patients were hospitalized as compared with 20 of 39 non-nursed patients. Those in the second severity class (having less than maximum disability plus major comorbidity) had fewer admissions to nursing homes in the presence of the nursing program (5 of 40 as compared with 15 of 46 in the program's absence). In the absence of both maximum disability and major comorbidity, more patients assigned to the nursing program were hospitalized (26 of 36) than those not so assigned (18 of 37); and those assigned to the nursing program received more non-nurse and non-physician professional services. In this case, 36 of 48 nursed patients received non-nurse and non-physician professional services in contrast to 28 of 50 non-nursed patients.

In this and the following paragraph, we present outcome with respect to *disability, mental function, and cardiovascular-renal disease*. Of patients who were severely disabled in terms of activities of daily living (grades *E, F, or G* by the Index of ADL), 75 of 100 were hospitalized in the presence of the nursing program as opposed to 50 of 97 in its absence. In the presence of the nursing program, patients in this same dependent category had more contacts with physicians during the two weeks before their terminal interviews (40 of 75 as compared to 27 of 75), had more non-nurse and non-physician professional services during the three months preceding the terminal interview (48 of 73 as compared to 34 of 72), more frequently died in a hospital (25 of 39 who died as compared to 13 of 32), and had more autopsies. Patients in the relatively less dependent category of activities of daily living (grades *A, B, C, or D* by the Index of ADL) had fewer admissions to nursing homes in the presence of the nursing program than in its absence. In this

subgroup, 1 of 27 nursed patients were admitted to nursing homes as opposed to 9 of 36 non-nursed patients.

Poor mental function and cardiovascular-renal abnormalities were among the important abnormalities included in the classification terms "coexisting major chronic condition" and "major comorbidity". Poor mental function was also represented in the major disability classes, since poor mental function was often the basis for major dependence in activities of daily living and the two were strongly correlated with each other. Poor mental function and cardiovascular-renal abnormalities were, thus, factors which contributed to the previously described significant outcomes for patients with major comorbidity or major dependence in activities of daily living. When we examined study results in patients classified according to mental function or cardiovascular-renal status without taking other disease or disability factors into account, we did not demonstrate differences in use of services between patients assigned and not assigned to the nursing program.

In summary, the findings in this chapter demonstrate that mildly or moderately disabled patients showed physical and psychological benefits in the presence of the nursing program, as did those with uncomplicated musculoskeletal disease and those who functioned adequately mentally. The mildly or moderately disabled group also had fewer admissions to nursing homes. Severely ill and disabled patients, on the other hand, did not show similar beneficial results, but made more use of hospital and other professional health services, as did those with complicated central nervous system or cardiovascular-renal disease. Decreased social interaction was a nursing effect experienced by those with poor mental function, and those with severe cardiovascular-renal disease. The foregoing were consistent and significant effects, not biased by introducing observers separately or in parallel with the nursing program (see summaries of "observation" and "interaction" effects in Chapter 11).

Discussions of nursing effects in both this chapter and in Chapter 9 are based on the most frequently encountered outcomes, where we

define the term "most frequently encountered" as any outcome which was statistically significant for at least five per cent of the study's Intake Classes (listed in Chapter 14). Significant outcomes which occurred less frequently (generally for only one or two of the 71 Intake Classes) were more likely to represent infrequent random occurrences and are summarized separately as follows. Nine of the 16 infrequent outcomes were in the same direction as frequently occurring outcomes, namely, more beneficial effects associated with the nursing

program, decreased social interaction, and greater use of services. The only infrequent outcome which occurred in as many as three Intake Classes was a beneficial nursing effect in terms of fewer deteriorations by the Raven test of observation and clear thinking. The descriptions in Chapters 7 and 9 are consistent with 93 per cent of the study's significant findings. The descriptions are, thus, not changed materially by information about infrequent outcomes and can be accepted with a high degree of confidence.

## CHAPTER VIII. CLASSIFICATION OF SOCIAL FACTORS FOR THE STUDY

An essential quality of chronic illness is its duration. The illness becomes a part of the continuing personal and social life of the afflicted individual, and factors in the social environment may contribute to the development of the illness and influence its course. A longitudinal study of chronically ill patients must, therefore, take account of social factors in describing the course of events and in evaluating the results of treatment.

In a review of "social psychological factors in illness", King observes that conditions or events in the social environment contribute to the etiology of disease and to the course of disease (1). Here, the relationship ranges from a clear-cut one, such as malnutrition resulting from culturally-determined dietary habits, to an indirect one such as the relationship between tuberculosis mortality and environmental factors, namely, housing and income. Although direct causal relationships between social factors and disease, or the course of disease, have been established in only a few instances, there are many demonstrated associations with social factors which have yet to be explained. This being the case, it is necessary for the investigator of a chronic disease to identify and measure those social characteristics which seem most relevant to the research question. In addition to previously defined primary groupings, patients in our study were, therefore, classified in terms of the following social characteristics as they entered the study: (1) *identifying social characteristics* (including social class, economic dependence, social role, and household composition), (2) *social interaction*, and (3) *social deprivation*. We present the description of the social categories in this chapter.

### *Identifying Social Characteristics at Intake*

Relationships between health and social factors

such as social class and economic status have been demonstrated in several fields as, for example, maternal and child health, general health and mortality, and chronic illness (2, 3, 4, 5). The study of social class and mental illness by Hollingshead and Redlich is of particular interest, since it demonstrates that treatment and outcome in comparable illness situations may also be correlated with social position (6).

We used several measures to define social characteristics of patients at the time they entered the study. As one measure, we selected Hollingshead's "Two Factor Index of Social Position" based on occupation and education (7). None of the available indices, including Hollingshead's, is well standardized for the kinds of elderly people seen in this study, many of whom represent fragments of the nuclear family which forms the basis of classification for many social indices. For this reason, we also used the "Index of Economic Dependence", which is a modification of a measure developed in the course of studying similar patients discharged from the same hospital (8). The measure is described in Chapter 5 and is based on the following three characteristics: (1) Financial support from a charitable agency, (2) employment status, and (3) home ownership. These economic factors are clearly both indicators of the financial situation in which a particular patient's illness occurs and measures of certain resources available for care. Classification of patients at intake was expressed in terms of the four classes of the index, Class 1 being economically the most independent and Class 4 the most dependent.

Social role or function may theoretically be distinguished from status or position. The roles of a man as worker and of a woman as homemaker are probably the most critical social functions for the elderly. Retirement from

either role alters an individual's socioeconomic function immediately and may eventually alter status through loss of income or increased expenses. Because of the importance of these roles in a group such as the present one, those who were actively working or homemaking until the illness for which they were hospitalized were identified as groups for separate study.

We classified household composition in terms of three categories, married and living with spouse, solo living with others, and living alone. "Solo" means unmarried, widowed, separated, or divorced. Marital status was included in the definition of household composition; since, for a sick or disabled person, his relationship to those with whom he lives strongly influences how much assistance he can expect from them. For this reason, also, we defined a separate category as "living with spouse or child".

#### *Social Interaction at Intake*

Man is a social animal, and every individual participates in many kinds of formal and informal contacts with other human beings. The number and variety of these contacts tend to diminish with age and illness. A few individuals choose lives of social isolation while more have it thrust on them.

Associations between illness and social isolation have been reported in such studies of the aged as those of Kutner and of Townsend (5, 9). In another report, mortality rates have been found to be lower for the married than for the single or widowed (10). The bases for these relationships between social status and health status are not well-established. Interpretation of the findings is hampered by difficulties in designing and conducting causal studies, as well as by problems of measuring social interaction. Terminology differs from one investigator to the next. For example, Cumming and Henry speak of "engagement" and use a "Social Lifespace" measure based on weighted scores for contacts with relatives, friends, neighbors, and others (11). Townsend uses a "scale of isolation" derived from the same kind of data (9). Kutner refers to "range of interpersonal relations" or "relative social isolation" based on broadly defined kinds of social interaction (5).

Based on the above ideas and in the absence of any standard measure, we collected a large number of observations bearing on social interaction (Forms A-2, A-3, A-4, and A-5 in Chapter 13). As the study progressed, we organized these data for purposes of analysis into a series of measures. Classes embodied in the measures were defined with the requirement in mind that they had to contain large enough numbers of patients to permit comparison between experimental groups.

The first measure was a scale of personal interaction, based on the number of kinds of individuals with whom the subject had daily contact. The kinds of individuals were classed as spouse, relatives, or friends; and the three grades of the scale were defined as daily contact with two or three categories of persons, with one category, and with none. This measure included contacts with people both within and outside of the household.

Three separate indicators were designated as measures of social activity or inactivity. These were "talks to more than five persons daily", "any regular organized social activities", and "employed during the two weeks prior to intake hospitalization". Finally, we synthesized an additional three indicators of interaction from the above elements of social interaction, namely, from elements of personal interaction and social activity.

#### *Social Deprivation at Intake*

Parkes reports that the loss of a husband increases the frequency with which widows consult their physicians for non-psychiatric symptoms (12). Townsend describes circumstances of subjectively perceived personal loss or "desolation" in older people and reports an increased death rate among the older widowed population, while Lowenthal and Boler describe a correlation between low morale and recent retirement, widowhood, and physical disability (9, 13). "Social deprivation" was the term we used to refer to this recognized, but not clearly defined, special form of isolation which is characterized by recent social losses of older people and which may be a precursor of loneliness (14).

The measures of social deprivation in our study included: "lost spouse in the two-year period prior to study", "retired within two years prior to admission to Abington House", and "ceased homemaking within two years prior to admission to Abington House". We also defined combined categories of the above measures of social loss. A rough measure related to the Cumming and Henry concept of "Perceived Life Space" was included to obtain more information about the impact of social loss on study results (11). This measure was "talks to fewer persons at intake than at age 45".

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## CHAPTER IX. EFFECTS OF TREATMENT PROGRAM: SUBGROUPS BY AGE, SEX AND SOCIAL CHARACTERISTICS

In the preceding Chapter, we presented the definitions and rationale for the social groupings of patients. In this chapter, we report significant associations between the treatment program and the outcome for subgroups of patients which were similar in *age, sex, identifying social characteristics, social interaction, and social deprivation* as they entered the study. In the first section of the chapter, we discuss effects of the nursing program in terms of function (physical, mental, and social), injury, and mortality. The second section of the chapter deals with the outcome in terms of use of services.

In relation to physical and mental function, evaluations of outcome were limited to systems of classification which identified improvement or maintenance (not improvement alone), since the study's main hypothesis was that function would be improved or maintained in the presence of the experimental care variable. As we discussed in Chapter 7, definitions of change in physical, mental, and social function excluded death as an item of change.

### *Outcome in Terms of Function, Injury, and Mortality*

Among certain subgroups which were homogeneous for age, sex, and social characteristics, statistically significant and consistent differences in function were demonstrated between patients who were assigned to the nursing program and those who were not. The most frequent outcomes in the presence of the nursing program were: (a) beneficial nursing effects in physical and/or mental function among the youngest (50-64 years), those who had been employed or homemaking before the present disabling illness, those who had not lived alone, those who had been socially active, and those who had been socially nondeprived; (b) increased house-confinement among men, those who were relatively independent economically, those who had lived with a spouse, and those who had been socially active; and (c) decreased social interaction among

the oldest, those who were relatively dependent economically, and those who reported a prior narrowing of social contacts.

The first groups of patients we shall discuss are those homogeneous in terms of *age* and *sex*. Patients who were 50 through 64 years old at the time they entered the study (the youngest patients) and who were assigned to the nursing program had fewer deteriorations in range of movement and fewer deteriorations in orientation and mental control than did similar patients not assigned to the nursing program (Table 9.1). For patients aged 65 through 74 years, the presence of the nursing program did not have any significant effect on function, injury, or mortality, while nursed patients who were 75 years old or older were more likely to decrease their participation in organized social activities than respective patients in the non-nursed group (15 of 35 patients in the nursed group and 6 of 43 in the non-nursed group). Concerning effects according to sex, increased house-confinement occurred more frequently among men in the nursed group (14 of 34) than among men in the non-nursed group (5 of 28).

We consider, next, outcome in patients classified according to their *identifying social characteristics* at the time they entered the study. Among patients who were relatively independent economically and patients who were married and living with a spouse, increased house-confinement was more frequent in the groups assigned to the nursing program than in the respective groups not so assigned. Of the 51 in the nursed group who were relatively independent economically, 16 became more confined to their homes in contrast to 6 of 47 in the non-nursed group. Among those who lived with their spouses, the respective numbers were 18 of 47 in the nursed group and 2 of 30 in the non-nursed group. Patients who had been

Table 9.1—Nursing Program Effect on Physical and Mental Function Two Years After Study Intake in Patients 50 Through 64 Years Old

	Patients 50 through 64 Years Old <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Range of Movement (upper limb)			
Deterioration <sup>2</sup>	0	6	6
No deterioration	31	24	55
Range of Movement (any limb)			
Deterioration <sup>2</sup>	2	9	11
No deterioration	29	21	50
Orientation and Mental Control			
Deterioration <sup>2</sup>	6	13	19
No deterioration	22	15	37

<sup>1</sup>Ages are the ages of patients as they entered the study.

<sup>2</sup>Deterioration in range of movement (upper limb) is Outcome Class #7 defined in Chapter 14. Deterioration in range of movement (any limb) is Outcome Class #9. Deterioration in orientation and mental control is Outcome Class #11.

employed or homemaking until they were hospitalized in Abington House had fewer deteriorations in the presence of the nursing program (3 of 35 patients) by the test of range of movement than in the absence of the program (14 of 50 patients). Fewer deteriorations by the test of orientation and mental control occurred among nursed patients who lived with people other than spouses (5 of 27 patients) than among similar non-nursed patients (15 of 35 patients). Patients who were relatively dependent economically and in the nursed group decreased social interaction more frequently (19 out of 48 patients) than did similar patients who were in the non-nursed group (12 of 59 patients), when the measure of social interaction was defined as the change in the number of organized social activities between the intake and terminal points of the study.

Classification of patients in terms of *social interaction* at the time they entered the study resulted in subgroups of patients who had been relatively active socially before the present illness, relatively inactive, or isolated. The most active subgroup had fewer deteriorations in range of movement in the presence of the nursing program than in its absence (Table 9.2). We defined a slightly less active class of patients, simply, as those who had had daily contacts with at least two of three categories of people (spouse, relatives, friends). The nursed patients in this subgroup showed more frequent increases in the degree of house-confinement (11 of 28) than did corresponding patients in the non-nursed subgroup (2 of 19).

As discussed in Chapter 8, we also classified patients as *socially deprived* or *socially nondeprived*. In comparisons of outcome, nursed patients in one of the socially deprived subgroups (specifically, those who had reported a narrowing of social contacts since age 45) more frequently decreased their participation in social activities in the presence of the nursing program

Table 9.2—Nursing Program Effect on Range of Movement Two Years After Study Intake in Socially Active Patients

	Socially Active Patients <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Range of Movement (upper limb)			
Deterioration <sup>2</sup>	0	5	5
No deterioration	23	9	32

<sup>1</sup>For this table, socially active patients are those who had daily contact with at least two of three categories of people (spouse, relatives, and friends) and who also either had talked to more than five people per day, had participated regularly in social activities, or had been working immediately before hospitalization (Intake Class #65 defined in Chapter 14).

<sup>2</sup>Deterioration in range of movement (upper limb) is Outcome Class #7 defined in Chapter 14.

(25 of 67 patients) than in its absence (12 of 77 patients). Patients who were socially nondeprived had fewer deteriorations in range of movement (Table 9.3).

#### *Outcome in Terms of Use of Services*

As we described in Chapter 7, hospitalizations and autopsies were more frequent among the 150 patients assigned to the nursing program than among the 150 not so assigned. This section deals with differences in use of services between subgroups which, at the time of entry into the study, were relatively homogeneous according to age, sex, and social characteristics. (As was naturally expected, more visiting nurse visits were received by all subgroups of patients who were designed to receive such service).

Among subgroups which were homogeneous for age, sex, and social characteristics at the time of entry into the study, the most frequent outcomes in the presence of the nursing program were: (a) more patients hospitalized among the oldest, those who had been socially active before the present disabling illness, and those who had recently been socially deprived; (b) more contacts with physicians among men, those in higher social classes, those who lived with a spouse, and those

who had been socially active before the present disabling illness; (c) more non-nurse and non-physician professional services among those who were relatively independent economically, those who did not live alone, and those who had been relatively active socially; (d) fewer nursing home admissions among those who had recently been socially deprived; and (e) more hospital services at the time of death among those who had been economically dependent, had been inactive socially, and had recently been socially deprived.

There was only one subgroup of patients grouped according to *age* for which we demonstrated a significant difference in use of services between those who were and were not assigned to the nursing program: more patients who were 75 years old or older were hospitalized in the presence of the nursing program than in its absence (Table 9.4). In this aged group, 72 per cent of those assigned to the nursing program were hospitalized (39 of 54) in contrast to 49 per cent of those who were not assigned to the nursing program (29 of 59).

The one difference which we demonstrated in nursed and non-nursed subgroups categorized according to *sex* was that significantly more men in the nursed group had contacts with physicians during the two weeks before their final study evaluations than men in the non-nursed group. Among men, 59 per cent of the 34 referred to the nursing program for the study had contacts with physicians, while the proportion was 29 per

Table 9.3—Nursing Program Effect on Range of Movement Two Years After Study Intake in Socially Nondeprived Patients

	Socially Nondeprived Patients <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Range of Movement (any limb)			
Deterioration <sup>2</sup>	10	21	31
No deterioration	56	49	105

<sup>1</sup>Socially nondeprived patients are those who had not lost their spouse in the 2-year period prior to the study or who had not terminated employment or homemaking between 30 days and two years before admission to Abington House (Intake Class #69 defined in Chapter 14).

<sup>2</sup>Deterioration in range of movement (any limb) is Outcome Class #9 defined in Chapter 14.

Table 9.4—Nursing Program Effect on Hospitalization During the Study in Patients 75 Years Old or Older

	Patients 75 Years Old or Older <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Hospitalized			
Yes <sup>2</sup>	39	29	68
No	15	30	45

<sup>1</sup>Ages are the ages of patients as they entered the study.

<sup>2</sup>Hospitalized during the study is the Outcome Class #19 defined in Chapter 14.

cent of the 28 who were not referred to the nursing program.

Considering patients grouped according to *identifying social characteristics*, those in relatively high social classes (Hollingshead's Index classes I, II, and III) and those married and living with spouse more often had contacts with physicians during the two weeks before their final study evaluations in the presence than in the absence of the nursing program. Those contacting physicians in the nursed group comprised 57 per cent of the 42 in high social classes (as opposed to 36 per cent of 45 in the non-nursed group) and 57 per cent of 47 married and living with spouse (as opposed to 32 per cent of 31 in the non-nursed group). During the three months preceding the terminal evaluations, the following nursed social subgroups received more non-nurse and non-physician professional services than did similar non-nursed subgroups: patients who were relatively independent economically (32 of 50 patients in the nursed group as compared to 18 of 45 patients in the non-nursed group) and patients who did not live alone (23 of 28 patients in the nursed group as compared to 20 of 37 patients in the non-nursed group). More autopsies were performed in the presence of the nursing program on deceased patients who had been economically dependent than in the absence of the nursing program (11 of 26 in the nursed group as opposed to 3 of 22 in the non-nursed group).

We discuss, next, outcome among patients classified for *social interaction*. Patients who had been socially active before their present disabling illness were more likely to be hospitalized in the presence than in the absence of the nursing program (Table 9.5). During the two weeks before the final study evaluations, significantly more contacts with physicians were made by nursed (18 of 28) than non-nursed (6 of 20) patients who had daily contacts with at least two of three categories of people (spouse, relatives, and friends). The subgroup of patients who were intermediately active (interacted daily with either spouse, relatives, or friends) received more non-nurse and non-physician professional services during the three months preceding the terminal evaluation in the presence than absence

Table 9.5--Nursing Program Effect on Hospitalization During the Study in Socially Active Patients

	Socially Active Patients <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Hospitalized			
Yes <sup>2</sup>	36	22	58
No	16	23	39

<sup>1</sup>For this table, socially active patients are those who had daily contact with one of three categories of people (spouse, relatives, and friends) and who also either had talked to more than five people per day, had participated regularly in social activities, or had been working immediately before hospitalization (Intake Class #66 defined in Chapter 14).

<sup>2</sup>Hospitalized during the study is the Outcome Class #19 defined in Chapter 14.

of the nursing program (39 of 58 patients as compared to 25 of 58 patients). Nursed patients who had participated regularly in social activities before entering the study were more often in hospitals at the time of death than similar non-nursed patients (15 of 20 patients as opposed to 5 of 14). More autopsies were performed at the time of death on deceased patients in the following nursed subgroup than on similar non-nursed patients: those who had daily contact with no one (7 of 10 in the nursed group as opposed to 0 of 5 in the non-nursed group).

Outcomes related to *social deprivation* are considered in this paragraph. Patients who had been assigned to the nursing program and who had suffered the deprivation of a recent loss of spouse or cessation of employment or homemaking were more likely to be hospitalized (Table 9.6) and had fewer admissions to nursing homes than similar patients who had not been assigned to the nursing program. In this class of patients, the respective numbers of admissions to nursing homes were 4 of 37 patients assigned to the nursing program as compared with 15 of

Table 9.6--Nursing Program Effect on Hospitalization During the Study in Socially Deprived Patients

	Socially Deprived Patients <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Hospitalized			
Yes <sup>2</sup>	35	27	62
No	12	22	34

<sup>1</sup>Socially deprived patients are those who had lost their spouse in the 2-year period prior to the study or who had terminated employment or homemaking between 30 days and two years before admission to Abington House (Intake Class #68 defined in Chapter 14).

<sup>2</sup>Hospitalized during the study is the Outcome Class #19 defined in Chapter 14.

44 patients not assigned to the nursing program. More autopsies were performed at the time of death on deceased patients of the nursed group who had recently retired or ceased homemaking than on similar non-nursed patients (7 of 12 as opposed to 1 of 11). Finally, we demonstrated the following significant differences between nursed and non-nursed patients who had narrowed their social contacts between age 45 and the intake point of the study: more patients hospitalized (Table 9.7), more in-hospital deaths and more autopsies at the time of death in the presence than absence of the nursing program (8 of 15 opposed to 1 of 14).

In summary, younger patients showed physical and psychological benefits in the presence of the nursing program, as did those who had not lived alone before the present disabling illness and those who had been employed, homemaking, or otherwise active socially. Decreased social interaction was a nursing effect experi-

Table 9.7--Nursing Program Effect on Hospitalization During the Study in Patients with Narrowed Social Contacts

	Patients with Narrowed Social Contacts <sup>1</sup>		Totals
	Referred to Visiting Nurse (N+)	Not Referred to Visiting Nurse (N-)	
Hospitalized			
Yes <sup>2</sup>	74	54	128
No	28	48	76

<sup>1</sup>Patients with narrowed social contacts are those who talked to fewer people than they had at age 45 years (Intake Class #70 defined in Chapter 14).

<sup>2</sup>Hospitalized during the study is the Outcome Class #19 defined in Chapter 14.

enced mainly by the oldest, recently socially deprived, and economically dependent patients. Patient subgroups which showed decreased social interaction were generally the same as the subgroups which had more hospitalizations and more hospital services at the time of death. Increased house-confinement was an effect for men living with a spouse, for those who had been socially active, and for those who were economically independent. Patient subgroups which showed increased house-confinement tended to be the same as the subgroups which used more physician and other professional services. Among those who had recently been socially deprived, fewer nursing home admissions occurred in the presence of the nursing program. The foregoing were consistent and significant effects, not biased by introducing observers separately or in parallel with the nursing program (see summaries of "observation" and "interaction" effects in Chapter 11).

## CHAPTER X. INTERVAL RESULTS

Chapters 7 and 9 dealt with treatment effects at the end of two years. In this chapter, we describe the times of appearance and durations of the treatment effects *during* the two year period of the study. Dates of death, injuries, admissions to nursing homes, and admissions to hospitals were identified for all 300 patients; thus, treatment effects with respect to these outcomes could be determined exactly and, according to the study design discussed in Chapter 2, without the bias of the observation process. With respect to physical, social, and economic functioning, as well as use of professional services, we identified treatment effects at scheduled times during the study, namely, semi-annually for social functioning and quarterly for the remaining types of outcomes. These outcomes could only be evaluated for the 75 treatment and 75 control patients who were scheduled for quarterly observations, and the evaluations were not available for the 150 patients who were not so scheduled. As discussed in Chapter 2, such treatment effects (determined only in quarterly observations) were subject to a possible observer bias or to a possible interaction bias (simultaneous presence of the observation process and treatment program). We describe interval results in the present chapter, therefore, under two headings, "Unbiased Interval Results" and "Interval Results Subject to Possible Bias".

Consistent with the approach used throughout the book to describe effects of the nursing program, discussions in this chapter are based on the most frequently encountered outcomes, where we define the term "most frequently encountered" as any outcome which was statistically significant for at least five per cent of the Intake Classes which were evaluated. As we described in Chapter 9, the great majority of infrequent outcomes were in the same direction

as frequently occurring ones and did not change interpretations concerning study results. Finally, a brief comment about the term "interaction" will help to avoid possible confusion arising from two uses of the term. The term "interaction bias" or "interaction effect" applies to an effect measured by the study design as described in Chapter 2, while the term "social interaction" refers to an area of social function.

### *Unbiased Interval Results*

Nursing program effects appeared six to twelve months after the treatment program was introduced. Starting at that time, fewer patients were admitted to nursing homes in the presence of the treatment program, and more were hospitalized. Survival did not differ significantly between treatment and control groups; and although fractures tended to appear earlier in the treated group, the actual number of such injuries did not differ between the two groups.

As previously stated, we could determine interval effects in terms of *death, injuries, admissions to nursing homes, and admissions to hospitals* exactly and without the bias of the observation process. During the course of the study, 29 per cent of the 300 patients died; 12 per cent sustained fractures; 20 per cent were admitted into nursing homes; and 57 per cent were hospitalized.

With respect to *mortality*, we did not demonstrate differences between those assigned to the nursing program and those not so assigned. In Figure X-1, we compare survival in nursed and non-nursed groups in graphs made with the aid of life table methods (1).

Nine months after the treatment program was introduced, *injuries* in terms of fractures appeared in certain subgroups more frequently in the presence of the nursing program than in its absence. This difference persisted for the next nine months, after which time we demonstrated

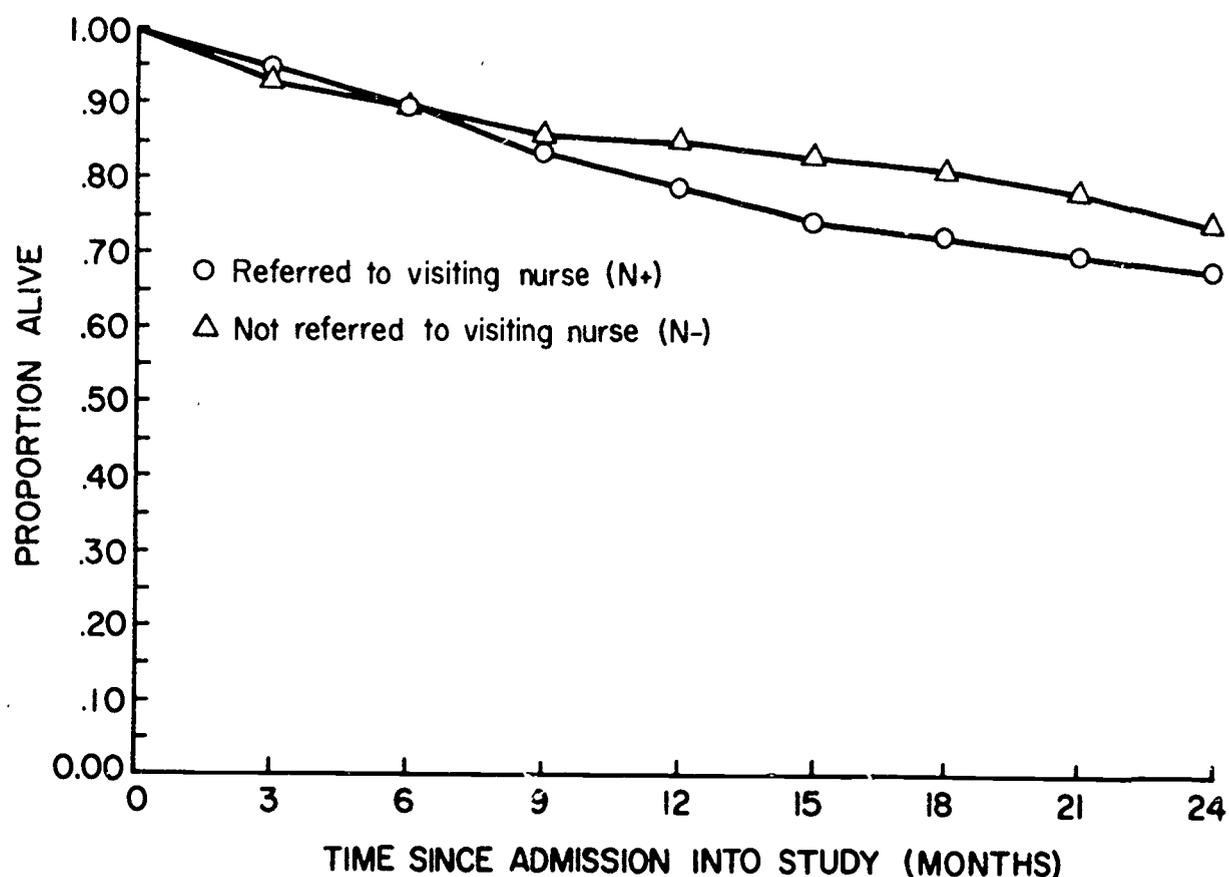


Figure X-1. Survival in Patients Referred and Not Referred to Nursing Program

no difference between treatment and control patients. Since the occurrence of fractures was analyzed as a cumulative event over time, disappearance of the difference between the treatment and non-treatment groups meant that there was no final difference in the actual number of fractures during the study; however, such injuries appeared earlier in the presence of the treatment program (Figure X-2). We noted the earlier appearance of injuries among people who had been employed or homemakers before the present disabling illness, among people who had lived alone and had not been socially active, and among those who were markedly disabled as they entered the study.

Six months after we introduced the treatment program, a treatment effect on *nursing home admissions* became apparent in certain subgroups (Figure X-3). At that time, fewer patients were admitted to nursing homes in the presence of the nursing program than in its absence; and,

with the exception of one 3-month period, this finding persisted in a significant number of subgroups during the final 18 months of the study. The number of subgroups which showed fewer nursing home admissions during successive 3-month periods varied from three to nine; and, with few exceptions, these subgroups were the same as or similar to the subgroups in which the nursing home effect was present at the end of the study. In Chapters 7 and 9, we described the subgroups with fewer nursing home admissions at the end of the study.

They included patients who were not maximally disabled, patients who were not maximally disabled and had indicators of major chronic conditions, and patients who had been recently deprived socially (widowed, retired, or ceased homemaking). Additional subgroups with fewer admissions during the course of the study included those who were least ill, those who lived with others, and those who were economically relatively dependent. Associated with the

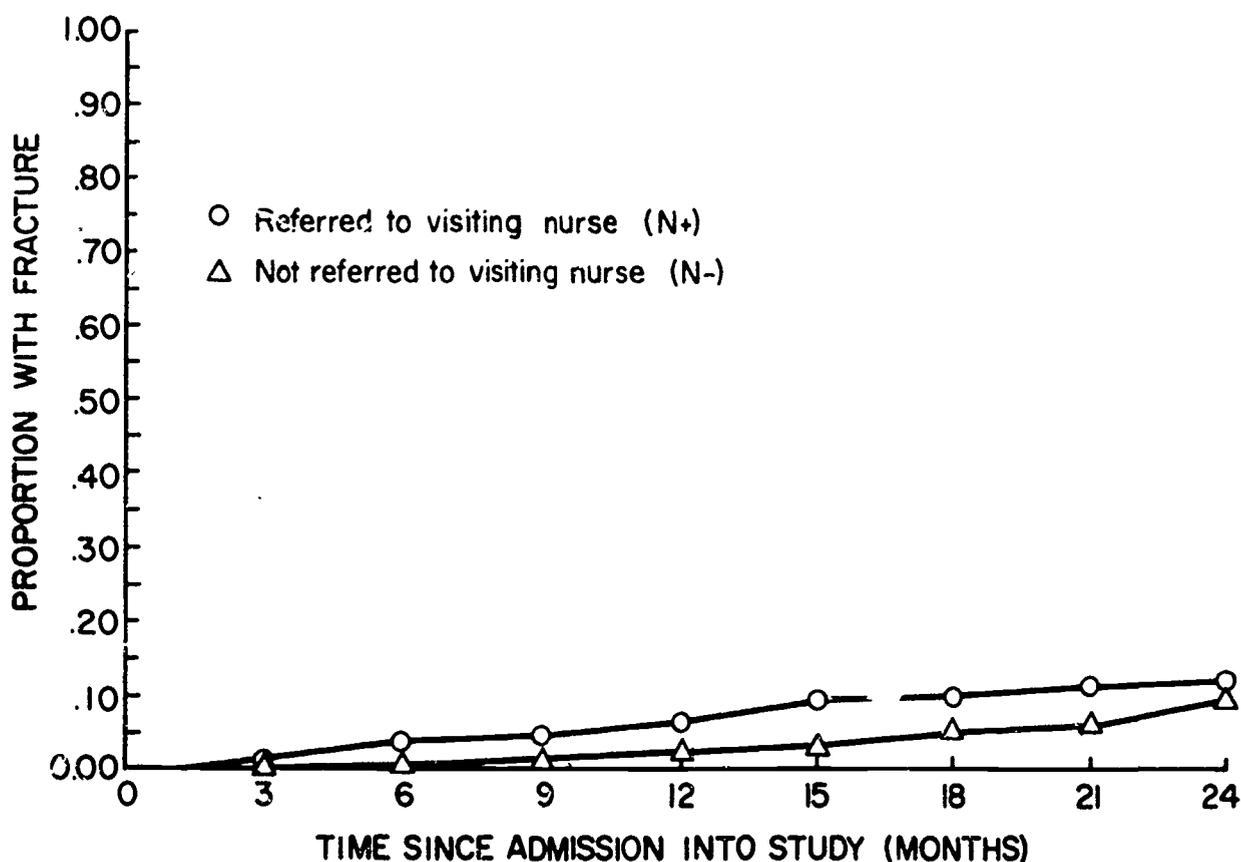


Figure X-2. Fractures in Patients Referred and Not Referred to Nursing Program

finding of fewer nursing home admissions, the percentage of days spent in nursing homes was consistently lower in the treatment group (Table 10.1).

Six months after the treatment program was introduced, a treatment effect on *hospitalizations* appeared, namely, more patients hospitalized in the presence of the nursing program than in its absence. Figure X-4 illustrates graphically the proportions of patients readmitted to hospitals after discharge from Abington House throughout the 2-year period of the study. This effect persisted through the end of the study, and the number of subgroups in which the finding was present during subsequent 3-month periods varied from 12 to 21. In Chapter 7, we observed that the effect with respect to hospitalizations applied to the total group of patients, as well as to subgroups. The hospitalization effect was strong. In addition to the fact that the effect for the total group was present in every quarterly interval after the first half year, 44 per

cent of the 71 subgroups showed this effect at sometime during the course of the study. The following were the prevailing subgroups: patients who had principal diagnoses of fractured femur with indicators of coexisting major chronic conditions, patients who had principal diagnoses of any lower extremity fracture with indicators of coexisting major chronic conditions, the most disabled patients, those without both maximum disability and indicators of major chronic conditions, women, patients aged 75 years or older, those in low socioeconomic classes, those who were relatively dependent economically, those who lived with others, those who had been moderately active socially before the present disabling illness, patients who talked with fewer people than they had at age 45, and patients who had not shown recent social deprivation (widowed, retired, or ceased homemaking). Though the number of patients who were hospitalized differed significantly between treatment and control groups, the percentage of

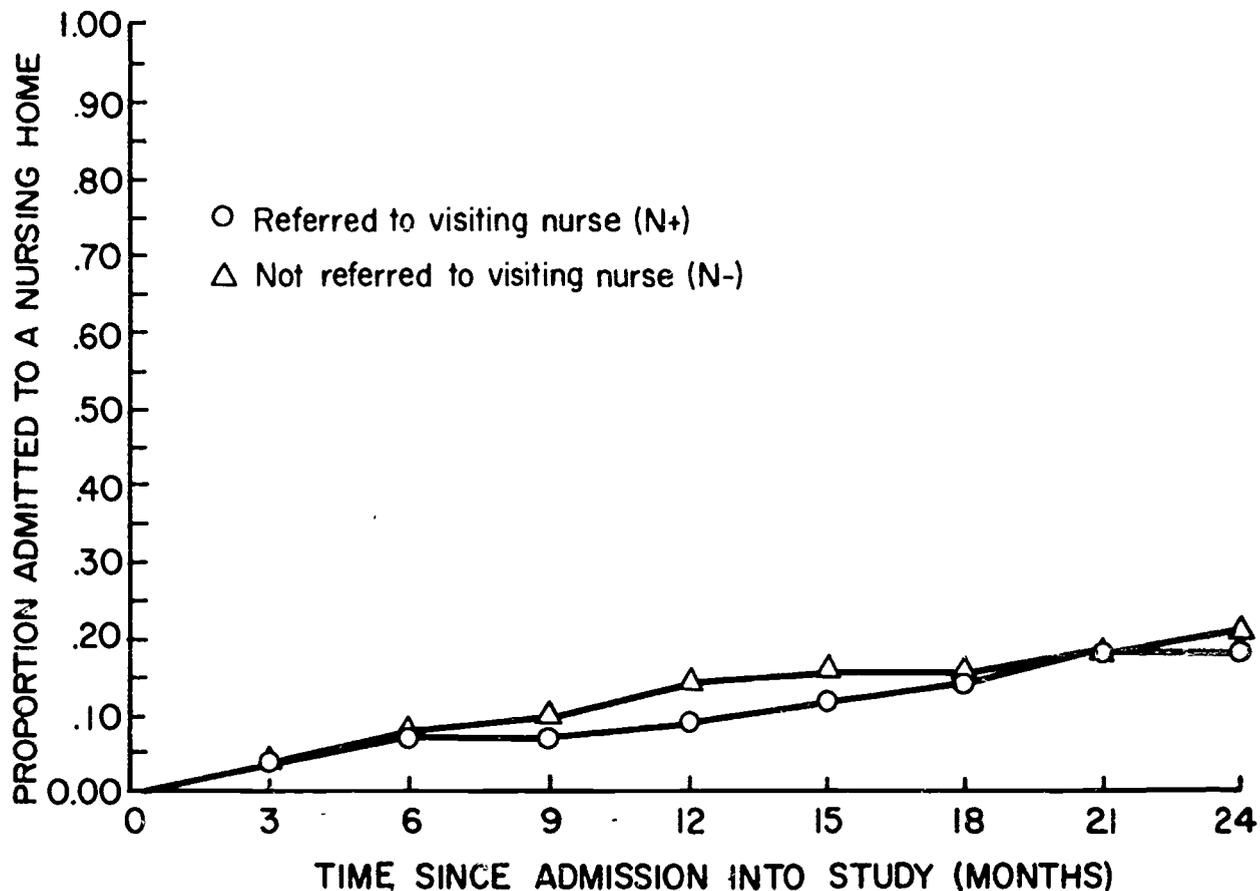


Figure X-3. Admission to Nursing Homes in Patients Referred and Not Referred to Nursing Program

days spent in hospitals was not notably different (Table 10.1).

#### *Interval Results Subject to Possible Bias*

The presence of observers did not seem to bias nursing program effects, but interaction between the observation process and nursing program tended to obscure some true nursing program effects during the intervals. Treatment effects which were not obscured and which were detected both during and at the end of the study included increased house-confinement, decreased participation in regular social activities, and more services from professionals other than physicians or nurses.

As we described earlier, conclusions about the true nursing program effects required measurements of the observer and interaction biases (defined in Chapter 2); and though this was not possible during the course of the study, the study design permitted such measurements at the terminal point of the study. By examining interval outcomes in the light of observer and interaction effects at the end of the study, we

could make limited interpretations about true nursing effects during the intervals on a defined and rational basis.

Interval evaluations were made of physical, social, and economic functioning, and also of use of professional services. On this basis, we demonstrated major interval effects in terms of the numbers of patients who became *more house-confined*, who showed *decreased social interaction*, who *returned to employment*, who showed *increased economic dependence*, who received *more home visits from physicians*, who had *more contacts with physicians*, and who received *more services from other professionals*.

*Increased house-confinement and decreased participation in regular social activities* occurred among patients who were assigned to both the quarterly observations and the nursing program, as compared to those assigned to quarterly observations and not to the nursing program. Increased house-confinement was intermittently

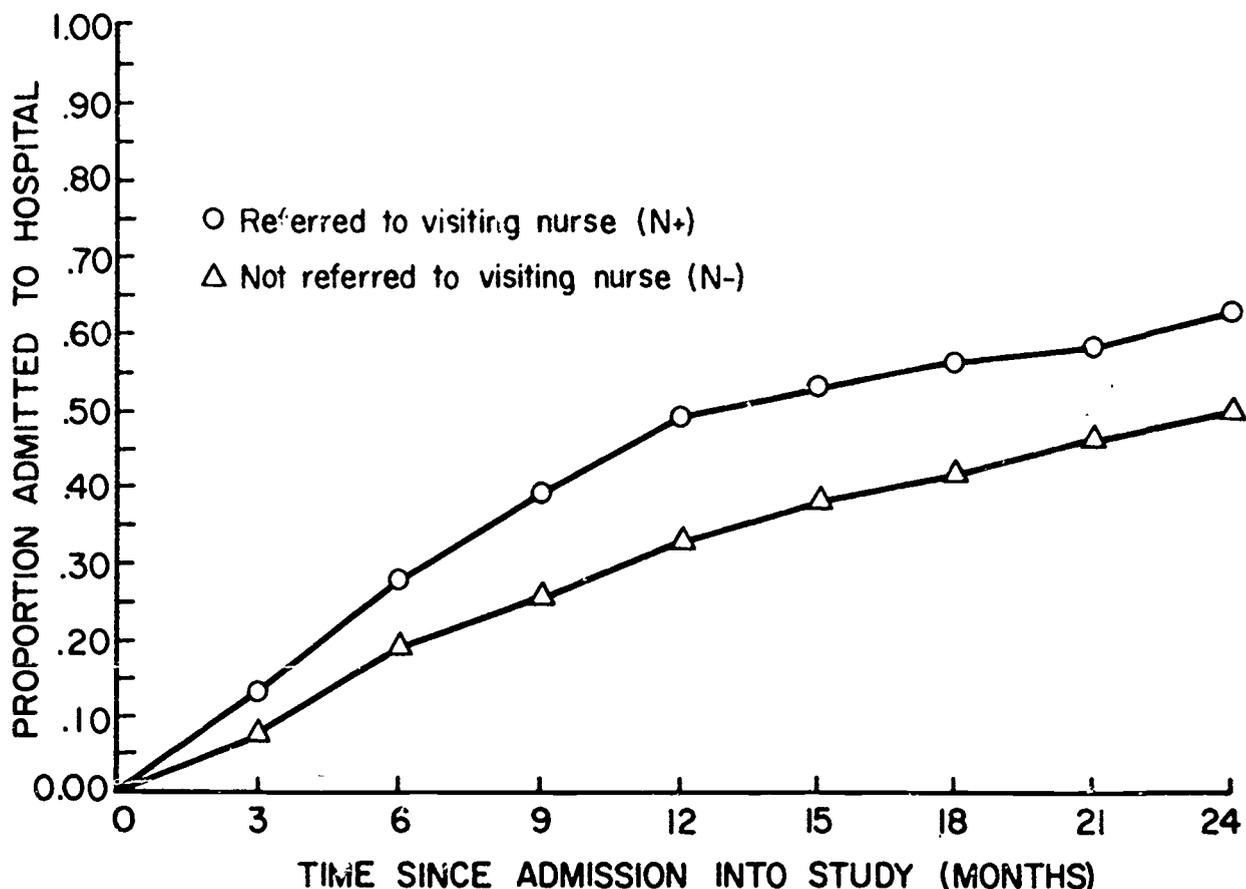


Figure X-4. Admissions to Hospitals in Patients Referred and Not Referred to Nursing Program

present from the third quarter through the end of the study, while decreased participation in social activities was intermittently present from the fourth quarter through the end of the study. Both effects were major treatment effects at the end of the study. Neither was an outcome associated with the observation process at the end of the study, and neither was an outcome associated with the presence of an interaction between the observation process and the treatment program. We could, thus, reasonably interpret the interval house-confinement and social participation effects as true nursing program effects. Increased house-confinement was an effect for the total group of observed patients and for certain subgroups. Included in the subgroups were patients who were most disabled, patients without both maximum disability and indicators of major chronic conditions, men, those who lived with a spouse, those who had been gainfully employed before the present disabling illness, those who were economically

relatively independent, those in high socioeconomic classes, and those who had been active socially before their present illness. Subgroups which demonstrated decreased participation in social activities as a nursing effect included patients who were not maximally disabled and had indicators of major chronic conditions, patients with major cardiovascular-renal conditions, patients with poor mental function, women, the oldest patients (75 years old or older), those who were economically relatively dependent, and those who talked to fewer people than they had at age 45.

We observed two socioeconomic outcomes during the course of the study which could not be interpreted as nursing program effects, namely, fewer *returns to gainful employment* and more patients with *increased economic dependence*, among those assigned to the quarterly observation process and nursing program in contrast to those assigned to quarterly observations alone. In analyses at the terminal point of

Table 10.1—Locations of Patients in Nursed and Non-Nursed Groups During the Study

Study interval (months)	Referred to Visiting Nurse (N+)			Not referred to Visiting Nurse (N-)		
	Hospital	Nursing home	Deceased or other	Hospital	Nursing home	Deceased or other
	(percentage of person-days <sup>1</sup> )					
0-3	10	1	89	10	1	89
3-6	6	3	91	3	6	91
6-9	4	5	91	3	6	91
9-12	4	5	91	4	9	87
12-15	4	8	88	3	11	86
15-18	3	7	90	3	10	87
18-21	2	8	90	5	11	84
21-24	4	9	87	4	13	83
Combined 24 months of study	4	6	90	4	8	88

<sup>1</sup>Percentages are the proportions of time spent by the entire group of patients in a given location. For a 3-month interval of 91 days, a group of 150 patients had a total of 13,650 (91 × 150) person-days of experience which were subdivided into percentages of time in the various locations. For the combined 24-month period of 730 days, a group of 150 patients had a total of 109,500 (730 × 150) person-days of experience which were subdivided into percentages of time in the various locations.

the study, these socioeconomic outcomes were neither nursing nor observer effects. They were interaction effects; therefore, as interval findings, they were probably, also, interaction effects. Confirmatory evidence was the fact that the subgroups which showed these interaction effects at the end of the study were similar to the subgroups which showed these outcomes during the intervals.

During the course of the study, patients assigned to the nursing program and quarterly observation process used more professional services than those assigned to quarterly observations alone. The increased use of professional services included *more contacts with physicians, more home visits by physicians, and more services from other professionals*. Two of these, namely, increased contacts with physicians and increased home visits by physicians, could not be interpreted as nursing program effects. In analyses at the terminal point of the study, where the various types of study effects were identified, increased contact with physicians was not an observer effect. It was both a nursing

program effect and an interaction effect. Subgroups which showed this outcome as a nursing program effect at the end of the study were unlike subgroups which showed the interval effect, while subgroups which showed the outcome as an interaction effect at the end of the study were similar to subgroups which also showed the interval effect. On this basis, we more reasonably interpreted the interval observation of increased contacts with physicians as an interaction effect. Increased home visits by physicians was, at the terminal point of the study, neither a nursing nor an observer effect. It was an interaction effect and so interpreted for interval observations, again confirmed by the similarity between subgroups which showed this effect during and at the end of the study.

Among patients assigned to the group which received both the nursing program and quarterly observations, increased use of professional services other than those of physicians and nurses appeared twice during the course of the study. This outcome appeared immediately after the treatment program was introduced (within the

#### Effects of Continued Care

first week after discharge from Abington House) and one year after the treatment program was introduced. Since the nursing program was barely in effect at the earlier time, we could not attribute the increased use of services from professionals, at that point, to the nursing program. It was more likely to be attributable to another factor such as the assignment process in the study, which involved several days of close work with patients' families in preparation for the introduction of the nursing program. At the later time, however, we could reasonably consider the increased use of other professional services as a nursing program effect. For this outcome, analyses at the terminal point of the study revealed a nursing program effect and did not reveal observer and interaction effects. Similar subgroups were, furthermore, involved during and at the end of the study. Included in the subgroups were patients without both maxi-

mum disability and indicators of major chronic conditions, the most disabled patients, women, those who were economically relatively independent, those who lived with others, and those who had been moderately active socially before the present disabling illness.

In summary, we detected the times of appearance of treatment effects during interval evaluations; and the design of the study permitted us to distinguish between interval treatment effects which were unbiased and those which were subject to possible observer or interaction bias. The evaluations revealed that the presence of observers did not bias nursing program effects, while some true nursing program effects were obscured by an interaction bias.

#### References

1. Chiang, Chin Long: *Introduction to Stochastic Process in Biostatistics*. Published by John Wiley & Sons, Inc., N. Y., N. Y., pp. 269-290, 1968.

## CHAPTER XI. INTERPRETATIONS

What significance can we attach to the findings of this study? To answer this question we must relate our findings to information from other sources, and to the parts of the health care process which deal with home care and nursing of the chronically ill. This chapter will attempt to place the results in these perspectives.

Before interpreting the findings, we must consider what general population our study population may represent. The process of selection of this sample and the composition of the sample have been described in Chapter 3. At this point, we must remind ourselves that we are considering what happened to a group of elderly, predominantly female, chronically ill patients who returned to the noninstitutional community from a chronic disease rehabilitation hospital. The hospital is in the category of specialty geriatric and chronic disease hospitals listed in the Master Facility Inventory of the National Center for Health Statistics (1). At the beginning of the study, 221 such hospitals were listed in the Inventory. Abington House was one of two which served most of Greater Cleveland's population. Patients in Abington House were similar to those in four other chronic disease hospitals (2) and were similar to patients in U.S. geriatric and chronic disease hospitals in that they were more disabled on the average than residents in nursing and personal care homes (3). Patients in our study differed from others in these comparison groups in one respect. Although people from all socioeconomic classes were included, a larger proportion had moderate to good financial resources.

The admission criteria in today's chronic disease rehabilitation hospitals are such that patients who are admitted are generally disabled and judged to have a potential for rehabilitation. Since not all who could benefit are afforded this rehabilitation opportunity, not all are repre-

sented in the present study. Those admitted to such hospitals, however, use a large amount of the nation's health service resources; and this group is represented in the study.

If we are to interpret the findings correctly, we must also consider certain kinds of bias to which they may be subject. The completeness of our data was excellent (Chapter 5), and the randomization process produced experimental groups which did not differ in respect to important characteristics at the beginning of the study (Chapter 12). Another possible source of bias which the study permits us to examine is the influence of introducing observer separately or in parallel with the nursing program. We refer to results which are related to these two factors as "observation effects" and "interaction effect", respectively. As stated earlier, the term "interaction effect" applies to an effect measured by the study design, and should not be confused with the term "social interaction" which is used to describe an element of social function. "Observation and interaction effects" are described, next, as a basis for understanding better than in the section, "effects of the nursing program," in which we summarize and discuss the effects of the service program.

### *Observation and Interaction Effects*

We identified outcome during the two-year study period that was related to the *presence of an observer* by contrasting the 150 patients who were assigned for quarterly observer visits with the remaining 150 who were observed only at the beginning and end of the study (Table 2.1). These findings have a bearing on the general problem of observational influence in studies of human behavior and are summarized here for the purpose of distinguishing observation effects from the effects of the nursing program.

With regard to function, injury, and mortality,

we did not find observation effects in comparisons between the 150 patients who were assigned for quarterly observer visits and the remaining 150 who were observed only at the beginning and end of the study. Among subgroups which were homogeneous for disease, disability, and mental function at the time of entry into the study, observation effects were distinctly less numerous than the nursing effects and quite different from them in character and direction (Figure XI-1). Compared to the nursing program, the process of observation had little effect on physical or mental function. Observation did, however, influence social function and admissions to hospitals, the principal effects being "fewer decreases in social interaction" and "fewer patients admitted to hospitals."

Although we designed the study to permit us to identify and measure observer effects, we did not design it to explain the basis for such effects. We consider it nevertheless appropriate to present a simple explanation suggested by our experiences in the study and by its findings, which could lead to a better understanding of the observation effects. The virtual absence of observation effects on physical and mental function probably reflected successful avoidance of a professional service role by the observer, a role which was strongly restricted by the training and supervision program for observers. However, the observer's visit and her interest in patient activities created an interactive situation, which was an unavoidable stimulus for social interactions. The observer who visited repeatedly and regularly may thus have taken on a secondary role, namely, that of a nonmedical friend, whose influence substituted social perspectives for medical or nursing perspectives which then affected decision-making concerning patients' problems. Since the observation process tended to maintain social interaction and to decrease hospitalizations, this explanation appears to offer an appropriate perspective from which to develop hypotheses about the observation effect.

The observer and care teams were kept separate throughout the study; yet, some statistically significant "interaction effects" ap-

peared. We identified these effects by contrasting the two groups in which the nursing program and the observation process were parallel (N+O+ and N-O- groups as defined in Table 2.1) with the two in which the programs functioned independently (N+O- and N-O+ groups). The interaction effect, therefore, was the study outcome which resulted from the combined influences of the nursing program and the observation process and which was not attributable to either in the absence of the other. Since treatment and observation were separate geographically, this effect is probably an indirect one as, for example, in the instance of a patient who discusses his problem with both a nurse and an observer and then acts differently than he would if he had talked to only one. Unless otherwise stated, we discuss in this section those results which were consistently associated with the presence of both programs (N+O+ component of the interaction effect).

Considering, first, the interaction and noninteraction groups which included all patients (150 in each group), we did not find differences in physical function, mental function, injury, and mortality. In terms of socioeconomic function and use of services, however, fewer in the interaction group returned to employment during the study than in the noninteraction group (Figure XI-2). Those in the interaction group also had more contacts with physicians and had more home visits by physicians during the last two weeks of the study.

Among subgroups which were homogeneous for disease, disability, and mental function at the time of entry into the study, the results of interaction comparisons show that, whereas the nursing program distinctly influenced physical and mental function, the presence of an interaction between the nursing program and observation process did not have such effects. (The first part of this section reported that observer effects were similarly not demonstrated for physical and mental function). Interaction effects were apparent, however, in the areas of social function and use of services, namely, fewer returns to employment, more physician services, and less non-nurse attendant care (Figure XI-2). A possible interpretation is that the

<u>Types of Patients<sup>1</sup></u>	<u>Types of Effects<sup>1</sup></u>
<u>Musculoskeletal Disease</u> without other chronic condition	fewer hospitalizations
<u>Central Nervous System or Cardiovascular-Renal Disease</u> with other chronic condition	fewer decreases in social interaction
<u>Severely Disabled</u> major assistance with self care	fewer decreases in social interaction
<u>Not Severely Disabled</u> with cardiovascular-renal disease or cancer	more decreases in social interaction; fewer hospitalizations
without cardiovascular-renal disease or cancer	fewer deteriorations in limb movement; fewer hospitalizations
without dementia	more decreases in social interaction; fewer hospitalizations
<u>Sex</u> male	fewer decreases in social interaction
<u>Economic Status</u> independent	fewer decreases in social interaction
<u>Household Composition</u> lives alone	fewer hospitalizations
<u>Social Interaction</u> active	fewer deteriorations in limb movement; fewer decreases in social interaction; fewer hospitalizations

<sup>1</sup>Classes of patients are defined in Chapters 6, 8, and 14. Types of effects are defined in Chapters 5 and 14. Listed effects are those which were most frequently encountered, that is, any type of observation effect which was statistically significant for at least five per cent of the study's Intake Classes (Chapter 14). Listed classes of patients are only those which showed these frequent effects.

Figure XI-1. Effects of the Observation Process

presence of both the nursing program and observation process tended to reinforce the sick role, as defined by Parsons (4). The fact that patients in this situation were less likely to return to work suggests that they felt "exemption from normal social role responsibilities," while the continued active contact with physicians could have arisen from their socially induced "obligation to seek technically competent help." This latter effect was in the same direction as the effect of the nursing program,

and may well represent a common element in the social and professional attitudes of observers and nurses, respectively. We consider, also, that social stimulation was a contributory factor to the interaction effects.

For a few subgroups, two findings were associated with the *absence* of both the nursing program and observation process (NO- component of the interaction effect) and could, thus, not be interpreted as findings due to the *presence* of interaction. These outcomes were:

Effects of Continued Care

<u>Types of Patients<sup>1</sup></u>	<u>Types of Effects</u>
<u>All Patients</u>	fewer returns to employment; more physician contact last 2 weeks; more physician home visits last 2 weeks
<u>Musculoskeletal Disease</u> with other chronic conditions	more frequent physician home visits
<u>Severely Disabled</u> major assistance with self care	less frequent non-nurse attendant care
<u>Not Severely Disabled</u> without cardiovascular-renal disease or cancer	fewer returns to employment; more increases in economic dependence; more frequent physician contact
without dementia	more frequent physician contact
no or minor assistance with self care	more frequent physician home visits
<u>Age</u> 65-74 years old	less frequent non-nurse attendant care
75 years old or older	more frequent physician contact; more frequent physician home visits
<u>Economic Status</u> independent	fewer returns to employment; more frequent physician contact
dependent	more frequent physician home visits; less frequent non-nurse attendant care
<u>Social Interaction</u> active	fewer returns to employment; more frequent physician contact
inactive	more frequent physician home visits
<u>Social Deprivation</u> not deprived	more frequent physician contact; less frequent non-nurse attendant care
deprived	fewer returns to employment; more frequent physician home visits

<sup>1</sup>Classes of patients are defined in Chapters 6, 8, and 14. Types of effects are defined in Chapters 5 and 14. Listed effects are those which were most frequently encountered, that is, any type of interaction effect which was statistically significant for at least five per cent of the study's Intake Classes (Chapter 14). Listed classes of patients are only those which showed these frequent effects.

Figure XI-2. Interaction Effects

more deteriorations in limb movement and in observation and clear thinking. It is interesting to speculate that these adverse effects may have resulted from the absence of systematic and objective decision-making which nurses or observers would introduce when evaluating patient problems.

#### *Effects of the Nursing Program*

The objectives of medical and nursing services are to maintain health, to prevent illness and its consequences, to treat illness, and to restore well-being. For patients who are chronically ill, services differ in important ways from services for those who have short-term diseases which are only infrequently associated with persistent impairment. We do not currently expect to achieve primary prevention (prevention of onset) of chronic disease. A more realistic goal is secondary prevention, that is, slowing of the disease process after it has begun and prevention of complications. In the treatment of chronic disease, preventive, therapeutic, and restorative services generally overlap; and continuing supervision is needed. The threats of chronic disease are physical, psychological, and social. Correspondingly, the services required are interdisciplinary; and interdisciplinary decisions and resources must be integrated through a cooperative process of assessment, service, reassessment, modification of service goals, follow-up, and follow-through. It is within the framework of these concepts that we discuss the effects of the nursing program in this section.

In Chapters 7, 9, and 10, we described in detail the changes in patient function and the changes in use of services which were attributable to the nursing program. In the present chapter, such changes are summarized in quantitative terms in Tables 11.1 through 11.4, which supplement the antecedent material. We shall discuss these results from three perspectives: (1) the *specificity of consequences* with respect to the type of treatment program and type of patient, (2) the *consequences* of the treatment program as an expression of its *coordinating activities*, and (3) the *consequences* in terms of *social function*. In this discussion, we interpret results with the caution required by the method-

ology of the study, including appropriate attention to the research strategy, availability of research measures, selectivity of research measures, and limitations of statistical inference.

The nursing program had *specific consequences* for patients with particular characteristics, and the types of consequences were related to the types of nursing program activities. A striking fact which is brought out by contrasting Table 11.1 with 11.2 is that the less disabled, less severely ill patients tended to show physical and psychological benefits, while the most disabled and severely ill received increased professional services. Younger patients were benefited in the same way as the less disabled, as were also those who functioned adequately mentally and those with uncomplicated musculoskeletal disease. Older patients received more services as did those with complicated central nervous system or cardiovascular-renal disease.

We are reminded by these observations of Parsons' statement that medical practice is a "mechanism in the social system for coping with illnesses of its members" and that the role of practitioners is "institutionalized about the technical content" of its activities or functions (5). Parsons uses the term "functionally specific" in referring to this concept, and findings in the present study are consistent with the concept. Both in the hospital where the study began and in the nursing program, special skills and resources were available for rehabilitation. We would expect, under these circumstances, that some of the disabled patients who were served could benefit from such resources, while others could not. We might also expect that specific benefits from the available specific treatment would be demonstrated most readily for those who were relatively less disabled and, thus, potentially more able to respond. Adaptation of service to the needs of the patient and to his capacity to respond is an important skill of the health professional. In a study of home nursing care, this was recognized by Johnson who referred to adaptation of service as the "differential opportunity open to the nurse" (6).

The findings of the study strongly confirm the foregoing assumptions and have important implications for several parts of the health care

Table 11.1—Quantitative Estimates of Nursing Program Effects on Function for Patients Classified by Disease, Disability, and Mental Status<sup>1</sup>

Characteristics on Admission to Study	Beneficial walking effect	Beneficial effect in limb movement	Beneficial effect in orientation and mental control	Decreased social interaction	Increased house-confinement
All Patients	—	—	—	—	—
Musculoskeletal Disease					
with other chronic condition	—	—	—	31	—
without other chronic condition	26	17-34	35	—	—
arthritis	—	47	—	—	—
Central Nervous System or Cardiovascular-Renal Disease					
with other chronic condition	—	—	—	—	—
without other chronic condition	—	—	—	60	—
Severely Disabled					
major assistance with self care	—	—	—	45	—
confined to house	—	—	—	—	—
unable to walk alone	—	—	—	—	—
restricted limb movement	—	—	—	—	—
Not Severely Disabled					
with cardiovascular-renal disease or cancer	—	14-27	—	—	—
with dementia	—	—	—	45-57	—
without cardiovascular-renal disease or cancer	16	16-17	—	—	—
without dementia	—	20	34	—	—
no or minor assistance with self care	—	13-25	27	—	—
not confined to house	—	10-12	—	—	—
walks alone	—	—	25	—	—
unrestricted limb movement	—	13	—	—	—

<sup>1</sup>Patient characteristics and program effects are those identified in Chapter 7.

Explanatory Note to Tables 11.1, 11.2, 11.3, and 11.4:

Each number in the following Tables represents the difference between the per cent who showed a specified outcome among those referred to the nursing program and the per cent who showed that outcome among those not referred to the program. In Table 11.1, for example, the figure of 47 per cent at the intersection of the row labelled "arthritis" and the column labelled "beneficial effect in limb movement" is obtained as follows. In the group of patients with arthritis who were assigned to the nursing program, 8 per cent showed deterioration in limb movement by the end of the study, while in the group of comparable patients not assigned to the nursing program, 65 per cent showed such deterioration. The difference, 47 per cent, is

taken as an estimate of the beneficial effect attributable to the nursing program. This figure means that, at the end of two years, approximately half the patients with arthritis who were assigned to home nursing care maintained limb movement which they would have lost had they not been given this care. Most of the results represent a difference between status at intake and at the end of the study and, therefore, refer to two-year survivors. For those outcome measures which were expressed as dates of specific events (e.g., injury, admission to nursing home, admission to hospital), both survivors and non-survivors were included; and the interpretation of such results considers whether or not the events occurred before death or the end of the study, whichever came first.

Table 11.2—Quantitative Estimates of Nursing Program Effects on Use of Services for Patients Classified by Disease, Disability, and Mental Status<sup>1</sup>

Characteristics on Admission to Study	Fewer Admitted to Nursing Homes	More Admitted to Hospitals	Increased Use of Professional Services			
			Physicians	Others	At Time of Death	
					Hospital Care	Autopsy
All Patients	—	12	—	—	—	41
Musculoskeletal Disease						
with other chronic condition	—	28-48	—	—	—	—
without other chronic condition	—	—	—	—	—	—
arthritis	—	—	—	—	—	—
Central Nervous System or Cardiovascular-Renal Disease						
with other chronic condition	—	—	27-43	32-40	51	—
without other chronic condition	—	—	—	—	—	—
Severely Disabled						
major assistance with self care	—	18-22	17-30	19-20	23	45
confined to house	—	—	—	—	—	—
unable to walk alone	—	—	—	45	—	—
restricted limb movement	—	—	28	—	—	—
Not Severely Disabled						
with cardiovascular-renal disease						
or cancer	20-21	—	—	—	—	—
with dementia	—	38	—	—	—	—
with cardiovascular-renal disease						
or cancer	—	24	—	19	—	—
without dementia	20	—	—	—	—	—
no or minor assistance with self care	21	—	—	—	—	—
not confined to house	—	—	—	—	—	30
walks alone	25	—	—	—	—	—
unrestricted limb movement	—	—	—	—	—	—

<sup>1</sup>Patient characteristics and program effects are those identified in Chapter 7.

system. Specific types of patients who benefited were identified; and terms of benefit were identified as, for example, "maintain strength, range of motion, and orientation and mental control." We, also, established quantitative estimates of the beneficial effects, in general, 10 to 47 per cent for physical function and 24 to 35 per cent for mental function (Tables 11.1 and 11.3). By thus adding specificity to existing concepts, our study contributes information about the directions and limits of effectiveness

of the nursing program. Study findings help nurses identify the types of patients who were benefited and the types who both were supported without apparent benefit and used more services. Efficiencies are, thereby, suggested for planning and allocating highly skilled and less skilled nursing services. Nurses should delegate many supportive service tasks to less highly trained new health personnel, and this study characterizes the likely categories of patients to be assigned to skilled and less skilled assistance.

Table 11.3—Quantitative Estimates of Nursing Program Effects on Function for Patients Classified by Age, Sex, and Social Characteristics<sup>1</sup>

Characteristics on Admission to Study	Beneficial walking effect	Beneficial effect in limb movement	Beneficial effect in orientation and mental control	Decreased social interaction	Increased house-confinement
Age					
50-64 years old	-	20-24	25	-	-
65-74 years old	-	-	-	-	-
75 years old or older	-	-	-	29	-
Sex					
male	-	-	-	-	23
female	-	-	-	-	-
Social Class					
high	-	-	-	-	-
low	-	-	-	-	-
Economic Status					
independent	-	-	-	-	19
dependent	-	-	-	19	-
Household Composition					
lives with spouse	-	-	-	-	32
lives with other than spouse	-	-	24	-	-
lives alone	-	-	-	-	-
Social Interaction					
active	-	36	-	-	29
inactive	-	-	-	-	-
Social Deprivation					
not deprived	-	15-19	-	-	-
deprived	-	-	-	22-29	-

<sup>1</sup>Patients characteristics and program effects are those identified in Chapter 9.

As a result, public health nurses could extend their capacity to fulfill the community's need for professional manpower which is in short supply. An implication of the findings for education is that a clear recognition of the kinds of professional goals which can be achieved with different types of patients should help simplify and rationalize professional education.

At the stage of chronic illness which most of the patients in this study had reached before being referred for care, goals of care were to interrupt or slow the regressive processes which

had already begun. This situation was recognized in the wording of the original hypotheses ("maintain or increase function"). Our results showed that *maintenance of function* or, more precisely, *avoidance of deterioration* was, in fact, the most consistent favorable effect, and that even this result could be achieved only with the younger and less disabled patients.

As previously stated, many patients with chronic illness are so severely disabled that the goal of treatment must shift from improving or maintaining physical and mental health to

Table 11.4—Quantitative Estimates of Nursing Program Effects on Use of Service for Patients Classified by Age, Sex, and Social Characteristics<sup>1</sup>

Characteristics on Admission to Study	Fewer Admitted to Nursing Homes	More Admitted to Hospitals	Increased Use of Professional Services			
			Physicians	Others	At Time of Death	
					Hospital Care	Autopsy
Age						
50-64 years old	—	—	—	—	—	—
65-74 years old	—	—	—	—	—	—
75 years old or older	—	23	—	—	—	—
Sex						
male	—	—	30	—	—	—
female	—	—	—	—	—	—
Social Class						
high	—	—	22	—	—	—
low	—	—	—	—	—	—
Economic Status						
independent	—	—	—	24	—	—
dependent	—	—	—	—	—	29
Household Composition						
lives with spouse	—	—	25	—	—	—
lives with other than spouse	—	—	—	28	—	—
lives alone	—	—	—	—	—	—
Social Interaction						
active	—	20	34	24	39	—
inactive	—	—	—	—	—	70
Social Deprivation						
not deprived	—	33	—	—	—	—
deprived	23-24	19-20	—	—	28	46-49

<sup>1</sup>Patients characteristics and program effects are those identified in Chapter 9.

copied with their everyday needs and periodic crises. It is not surprising that, for a group of patients who are unable to perform independently such ordinary activities as bathing, dressing, and using the toilet, the efforts of nurses and others around them are directed mainly at management rather than treatment. If the natural course of events cannot be altered for such patients, the public health nurse can at least assure that they have access to other professional services when crises occur and when

regression proceeds. For the severely disabled patient, then, the public health nurse is expected to increase the patient's access to hospitals, doctors, and other health workers.

Posman and co-workers conducted a prospective, experimental study of public health nursing services for patients over the age of 60 discharged from a public chronic disease hospital. In this group of patients, who differed from those in our study mainly in social and economic status, Posman identified a large disabled

subgroup for whom no favorable effects on health, physical functioning, or employment could be demonstrated but for whom the nurses were instrumental in improving access to hospitals and other professional services (7).

The effects of the nursing program on use of services in our study are summarized in Tables 11.2 and 11.4. Use of hospitals and services of other health professionals was increased in the presence of the nursing program, especially for persons who were older, more disabled, and more severely ill. Among these people, quantitative estimates of increased use of physicians and hospitals varied from 17 to 48 per cent, generally being 25 per cent or greater. Autopsies were also more frequent among such individuals, probably secondary to increased hospital admissions. Admissions to nursing homes, on the other hand, were less frequent among those in the nursed group, particularly those who were less disabled and who, as indicated previously, avoided deterioration more successfully when they were exposed to the nursing program (20 to 25 per cent fewer admissions in Tables 11.2 and 11.4). The percentage of days spent in nursing homes was correspondingly less for the treated group. These outcomes with respect to use of services were consequences of the presence of the nursing program, and they illustrate the selective application of coordinating activities, confirming the "functional specificity" of the program which we discussed earlier in this section.

The management of chronic illness is interdisciplinary, and the function of the public health nurse as a *coordinator of services* has been recognized in official statements as well as in practice (8). One follow-up study of rehabilitation patients in New York City showed that they and their families had great need for help in finding and coordinating services, including care by physicians and hospitalization (9). A common criticism of the health care system in the United States is that it is badly fragmented (10). The elderly, chronically ill individual at home is, furthermore, particularly likely to be unaware of or to lack access to persons and institutions who might care for him. The public health nurse is in a strategic position to help such patients make

contact with doctors, other health services, and hospitals. Our study reveals the circumstances in which interdisciplinary contacts of this kind were established. Since extended professional services were obtained primarily for patients with the greatest limitations and those least likely to demonstrate beneficial outcomes, it appeared that the functions of professional services for these patients were not sought primarily for physical cure or amelioration. In this connection, we note that increased use of professional services appeared six to twelve months after the treatment program was introduced. The findings suggest that such services were required in order to manage the crises and regressive processes that occurred, as well as to share the responsibility for difficult decisions and for providing burdensome care. For example, reports of the nurses' activities showed a high proportion of psychosocial care (Chapter 4) which consisted, in many cases, of counselling the patient and family about such major decisions as hospitalization or admission to a nursing home. If we accept this interpretation, it implies that services for this type of patient should be organized with less of the traditional emphasis on diagnosis, treatment, and consultation and more on planning, guidance, and interdisciplinary communication. Viewed thus, it may quickly become apparent that a balanced approach to service for many chronically ill persons should include homemakers, "sitters," friendly visitors, and day care centers, as well as doctors, nurses, and hospital beds. Current emphases on doctors, nurses, and hospital beds may, in fact, be out of balance when measured against needs for social and psychological supports. The need for "institutional" care of the totally disabled will remain with us; but this could be provided less expensively and more humanely if, after adequate evaluation and trial, certain wasteful efforts were set aside and the provision of decent living conditions substituted, with easy access to professional services for crises.

In the present study, *decreased social interaction* and *increased house-confinement* were outcomes which we attributed to the presence of the nursing program. Decreased social interaction was experienced mainly by the oldest

patients, those receiving much assistance with self care, those with cardiovascular-renal disease, those with poor mental function, socially deprived patients, and economically dependent patients (Tables 11.1 and 11.3). Since social interaction is a complex phenomenon that has its origins in an extensive combination of physical, psychological, social, and economic factors, the direction of change in the interaction (increase or decrease) does not indicate clearly whether well-being of the patient increases or decreases. Though increased social interaction may, at first glance, appear to reflect increased well-being, restricted interaction seems more appropriate for many very disabled people. Senile people, for example, require protective geographic restriction; and chronically ill and very old people may need protection to prevent accidents, such as falls which cause hip fractures. Social interaction for the infirm is often predominantly concerned with meeting their physical needs and with protection. Though this may be interpreted as proper "disengagement" from activities which are appropriate to younger people (11), our societal behavior tends to emphasize the physical network of support more clearly than the psychological and social network. In this discussion of social interaction, we have arrived at the same conclusion about social and psychological needs of old and very disabled people as we did in the discussion of increased use of services for these people. The findings also suggest that, among other risks, the professional process may reinforce inappropriate dependency for certain patients.

The related finding among treated patients was increased house-confinement for socially active, economically independent men who lived with a spouse. The composite of these characteristics suggests a pattern of life in which the occurrence of a major disabling disease (as did, in fact, occur) would be a desolating event. In addition, the same types of patients had increased contacts with physicians and other health professionals (Tables 11.3 and 11.4). A discussion of the interpretation of these observations resembles the preceding discussion of explanations about decreased social interaction and increased use of professional services. Possi-

ble explanations in terms of treatment functions, thus, include providing increased protection and reinforcing the patient's sick role. In addition, an active, economically independent man who suffers a disabling illness requires a different type of adjustment, for example, from a housewife who may continue to be partially involved in homemaking activities even after a disabling illness. The opportunity to accept the sick role may serve as the social process by which this man redefines his place in society. We are reminded, also, of Marden's observation that "impaired women possess more 'insulation'" than men (12). Of interest is the observation that increased use of professional services, decreased social interaction, and increased house-confinement appeared concurrently six to twelve months after the nursing program was introduced. Our explanations of these outcomes suggest that professional services may be asked to substitute for social and psychological supports which society has not provided. We question whether professional services alone are the best way of meeting these needs and suggest, as stated earlier, that less skilled assistance should be assigned to certain categories of patients.

Continued care at home, the subject of this book, is an important element of neglected primary services for a segment of the population which cannot speak effectively about its needs and which uses a large amount of the nation's health service resources. For a field which needs development, material in the book about the expected results of home care adds to the base of fact on which rational planning and action should proceed. The information will, also, be useful to practitioners and teachers. Use of the experimental method in a manner which is, thus far, unique in studies of "real world" health service programs adds a large measure of confidence to the results. In the remainder of the book (Chapters 12, 13, and 14, and the Appendix), we describe the study methods in expanded form.

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# PART II

*methods*

## CHAPTER XII. STATISTICAL METHODS

This chapter is concerned with the statistical aspects of the study and the drawing of valid conclusions therefrom. The methods of statistical analysis and the strength and validity of the conclusions depend greatly on the experimental design and the rigidity with which we followed this design. Accordingly, the experimental design described in Chapter 2 is re-examined in this chapter from a more technical point of view. We shall, also, examine the extent to which the execution of the study actually conformed to the experimental design, the methods of analysis, and their relevance to the purpose of the study and to the experimental design.

### *The Experimental Design*

The successes achieved by the science of Physics through the experimental method have largely resulted from the physicist's ability to identify and manipulate, at his pleasure, important variable factors in his experimental studies. The physicist often has the advantage of working with material that is homogeneous. His ability to express results quantitatively and in the form of equations allows him to predict results accurately under a variety of circumstances, and to build up gradually and increasingly inclusive theoretical framework.

The biomedical sciences must deal with the huge amount of variation inherent in biological organisms. Since no two people are exactly alike, a treatment that is successful for one patient may not be successful for another patient with the same illness. The multiplicity of factors affecting individuals in various degrees, and at various times, all too frequently makes it exceedingly difficult to identify important indi-

vidual factors. For studies involving people, social customs, laws, and ethical considerations often prevent the experimental manipulations of factors suspected to be of importance.

In experiments involving people, then, it is usually impossible to identify and control adequately all the important extraneous factors capable of affecting the experimental results. Fortunately, when the experimental method is to be applied, there is recourse to the process of randomized allocation of subjects. By this random process, the various factors, important and unimportant, known and unknown, are each expected to occur in equal proportions in the experimental groups. Their influences on outcome will, on the average, be the same in each group; and a scientific assessment of the relationships between treatments and outcomes is possible.

We assigned each of the 300 patients entering the present study, at the time of his entry and strictly on a random basis, to one of four groups which were referred to as "primary groups." These consisted of the four possible combinations of the two experimental variables, namely, the nursing program and the observation process. We adopted the symbols shown on the following page for the primary groups.

The 150 patients in the N+O+ and N+O- primary groups were scheduled to be visited regularly at home by a VNA nurse, while those in the remaining two primary groups were not. Every patient in the study was scheduled to be interviewed at "intake" when he entered the study, and at "termination" when he left the study two years later. In addition, the 150 patients in the N+O+ and N-O+ primary groups

Primary group symbol	Combination of experimental variables		Number in primary group
	Referred to nursing program	Quarterly observation process	
N-O-	absent	absent	75
N+O+	present	present	75
N+O-	present	absent	75
N-O+	absent	present	75

were scheduled to be interviewed at home every three months for a period of two years and were scheduled to have a post-discharge interview one week after entry into the study. The 150 patients in the other two primary groups were not scheduled for such interval evaluations. With few exceptions, each of the 150 patients in the N+O+ and N-O+ primary groups had the same interviewer throughout the study, but had a randomly assigned different interviewer for the terminal interview. Each of these 150 patients was scheduled to be interviewed twice at the end of the study, once by the randomly assigned new observer and a week later by the regularly assigned observer, for reliability and interval comparison purposes. Since patients shared common reference points in time (entry, quarterly observations, termination), their dates of entry could be transformed to a common starting or zero point; and all subsequent events on the time scale could be referred to the zero point. The patients thus comprised a cohort, and those in prospectively defined subgroups comprised subsets of the cohort.

The process of random assignments to the primary groups guaranteed that each patient had an equal chance of being assigned to any of the groups. It also guaranteed that extraneous factors (large or small, important or not, known or unknown) would, on the average, be equally distributed among the four primary groups. The practical consequence of the foregoing theoretic statements is that patients in the four groups were expected to be as similar as possible. We expected, for example, that patients with histories of serious heart disease would be equally distributed among the four groups, as would

men or those who preferred radishes to cucumbers.

Random assignments were accomplished with the aid of a table of random numbers. For each of 15 successive blocks of 20 patients, the randomization process equalized the numbers of patients in the primary groups. We designed this sequential blocking to prevent extended series of patients being assigned to the same study groups over the 22-month intake period. Sequential blocking, also, permitted us to examine findings in successive groups over time in order to detect differences in findings which might be associated with such external changes as new treatments, environmental changes, and new legislation such as Medicare. (Comparisons of findings for the first patients entering the study against findings for the last did not reveal marked differences.)

As we described in Chapter 2, the four equal-sized primary groups were pooled in various combinations, so that we could distinguish several types of effects. The following combined groups, called "experimental groups", were defined as shown on the following page.

Since the primary groups were formed at random, it follows that the experimental groups were also constructed in a random manner. Each patient, thus, had an equal chance of being assigned to any of the experimental groups, and extraneous factors would, on the average, be equally distributed among the experimental groups, e.g., age, sex, state of health, etc.

Comparisons between experimental groups were used to determine various effects in the study, and we discuss such comparisons and effects in the next section. The following effects were defined as shown on the following page.

The reader will note that we adopted the following format with respect to the use of symbols in this chapter. Primary groups are designated by both an N and an O, each followed by an algebraic sign. Symbols for experimental groups include a single algebraic sign which is not enclosed by parentheses, while symbols for effects are either without algebraic signs or with such signs enclosed by parentheses.

#### *Experimental Effects*

The purpose of the study was to determine the

Experimental group	Experimental group symbol	Combination of primary groups	Number in experimental group
referred to nursing program	N+	N+O+ with N+O-	150
not referred to nursing program	N-	N-O+ with N-O-	150
quarterly observation process	O+	N+O+ with N-O+	150
no quarterly observation process	O-	N+O- with N-O-	150
"plus" interaction	NO+	N+O+ with N-O-	150
"minus" interaction	NO-	N+O- with N-O+	150

Experimental effect	Experimental effect symbol	Experimental groups compared
nursing program	N	N+ against N-
observation process	O	O+ against O-
interaction	NO	NO+ against NO-
nursing program in presence of observation process	N(O+)	N+O+ against N-O+
nursing program in absence of observation process	N(O-)	N+O- against N-O-

consequences of the nursing program with regard to various outcomes, at various times, and for various people. If there were no interaction between the nursing program and observation process, the comparison of N+ against N- would yield a valid measure of the nursing program effect, since the presence or absence of systematically repeated observations was balanced equally between the N+ and N- experimental groups. Similarly, the comparison of O+ against O- would yield a valid measure of the observer effect, since referral or non-referral to the nursing program was balanced equally between the experimental groups O+ and O-. If an interaction between the nursing program and observation process did occur, the consequences of the nursing program would not necessarily be reflected in a comparison between the N+ and N- experimental groups, since interaction between the nursing program and observation process was a potential source of bias in one-fourth of the sample (primary group N+O+) and was not equally balanced between the experimental groups.

Stated in another way, we must know whether the nursing program and observer effects were independent of each other if we would make interpretations about the consequences of the nursing program from comparisons between those assigned and not assigned to the program. Though the sole function of observers was to gather data and though every effort was made to ensure that nurses and observers operated independently of one another (separate housing, secretarial staff, administrative staff, special liaison agents, etc.), certain interacting effects could have occurred. As stated earlier, a patient seen regularly by a nurse and not interviewed regularly could have behaved differently from a similar patient who was seen regularly by a nurse and also interviewed periodically.

When an interaction effect was present, the interaction factor in the N+O+ primary group invalidated the N+ against N- comparison as a measure of the nursing program effect. A less biased comparison was needed. The unbiased comparison between the N+O- and N-O-

primary groups served this need, and such data were available at the terminal point of the study; however, this comparison could not be used for quarterly interval data whose source, by definition, was the observers. Use of the terminal unbiased comparison entailed a reduction in total sample size from 300 to 150, a reduction which was rarely required in the present study. Significant effects of the nursing program based on the unbiased comparisons are presented in Chapter 11 and in the Appendix for 2 year results, and in Chapter 10 for interval results.

#### *Intake Classes and Effectiveness of Randomization*

Upon entering the study and before being randomly assigned to study groups, patients were systematically described by the observers. Classes of patients with similar characteristics (e.g., men, women, patients 75 years old or older) were defined and were termed "intake classes." We used the intake classes to test the effectiveness of the randomization process and to compare experimental findings between similar subgroups of patients. Another set of classes was established for use in identifying changes due to the treatment program, i.e., "outcome classes," which we shall discuss later in this chapter.

A total of 71 intake classes were established prospectively as relevant to the study. We discussed these physical, psychological, and social classes and their conceptual origins in Chapters 6 and 8; and detailed definitions are found in Chapter 14 (Intake Classes #1-#71). At the end of the study, 19 other classes were formulated in order to check the randomization process and study findings. Such checks validated the process and findings and, unless otherwise stated, results reported in this book concern only the 71 intake classes which were defined prospectively.

In order to determine the extent to which small changes in intake class definitions affected the study results, we designed certain intake classes to be closely related to others. Overlap between intake classes was evaluated with the aid of correlation coefficients which were calculated as follows:

$$r = [\Sigma(x-\bar{x})(y-\bar{y})] / \sqrt{([\Sigma(x-\bar{x})^2] [\Sigma(y-\bar{y})^2])}$$

Where,  $x = 1$  or  $0$  when the patient is *in* or *not in* the first class, respectively,

$y = 1$  or  $0$  when the patient is *in* or *not in* the second class, respectively,

$\bar{x}$  = the mean of the  $x$ 's, and

$\bar{y}$  = the mean of the  $y$ 's.

The correlation coefficient,  $r$ , ranges between  $-1$  and  $+1$ . If  $r = -1$ , the two intake classes are mutually exclusive (no overlap), and patients in one of these classes are not in the other. If  $r = 0$ , then the two classes are uncorrelated, and patients in one of these intake classes are randomly in or not in the other class. If  $r = +1$ , the two classes are identical (complete overlap), and patients in one of these intake classes are also in the other. In general, the greater the correlation coefficient, the greater the overlap.

We calculated the correlation coefficients for all possible pairs of the 71 intake classes and considered a correlation coefficient of  $+0.75$  to indicate major overlap. By this definition, we identified thirteen sets of intake classes where each intake class in a given set was highly correlated with at least one other intake class in that set. The thirteen highly overlapping sets are listed on the following page, and brief descriptions are included in order to clarify the nature of designed overlap.

As stated previously, we expected the randomization process to produce similar primary groups and similar experimental groups. We expected, thus, that proportions of patients in the individual intake classes or in combinations of intake classes would be the same for the four primary groups (N-O-, N+O+, N+O-, N-O+) and for the three pairs of experimental groups (N+ and N-, O+ and O-, NO+ and NO-). The extent to which the randomization process was effective was checked by chi-square tests applied to contingency tables in which the distributions of intake characteristics were compared between study groups. For example, the distribution of men and women among study groups is presented in Tables 12.1 and 12.2. Chi-square tests applied to these tables revealed no significant difference in the distribution of men and women among the primary groups or between the

Intake classes with designed overlap (by Intake Class #)	Description of set (see Chapter 14 for detailed definitions)
3, 5, 7, 9, 11, 25, 27	same degree of mild to moderate disability: different combinations of cancer and indicators of cardiovascular-renal disease
4, 6, 8, 10, 12	same degree of mild to moderate disability and no cancer: without cardiovascular-renal disease by various combinations of indicators of disease
13, 17	same degree of mild to moderate disability: different levels of mental function
15, 21	same degree of mild to moderately severe disability: different levels of mental function
18, 22	same degree of dementia: different degrees of severe disability
24, 26	same type of cardiovascular-renal disease and no cancer: different combinations of disability and dementia
28, 30, 32, 41	same type of comorbidity: different combinations of principal diagnoses of the central nervous system and cardiovascular-renal system
29, 31, 33, 42	same absence of comorbidity: different combinations of principal diagnoses of the central nervous system and cardiovascular-renal system
34, 36, 38	same type of comorbidity. different combinations of principal diagnoses of musculoskeletal
35, 37	same absence of comorbidity: different combinations of principal diagnoses of lower extremity fracture
53, 68	similar type of role deprivation: different in terms of loss of spouse
59, 65	same type of contacts with spouse, relatives, and friends: different degrees of other social interaction
61, 67	same absence of daily contacts with people: different degrees of other social interaction

experimental groups (at statistical probability levels of 0.05). As another type of example, we present in Figure XII-1 the distribution of ages among those assigned and not assigned to the nursing program. The observed age distributions were not significantly different.

Actual and expected percentages of statistically significant chi-square tests for intake class

characteristics are compared in Table 12.3. The similarity between actual and observed percentages demonstrates that the randomization process was very effective in distributing the 71 prospectively defined intake characteristics and, theoretically, other extraneous factors equally among the study groups. Among the few differences which we identified, the 150 patients

Table 12.1—Comparison of Numbers of Men and Women Among Primary Study Groups<sup>1</sup>

Primary groups	Men	Women	Totals
N-O-		53	75
N+O+	31	45	75
N+O-	22	53	75
N-O+	25	50	75
Totals	99	201	300

<sup>1</sup>Men and women are Intake Classes #43 and #44, respectively, as listed in Chapter 14. Symbols are defined in the text (Chapter 12).

Table 12.2—Comparison of Numbers of Men and Women in Experimental Study Groups<sup>1</sup>

Experimental groups	Men	Women	Totals
N+	52	98	150
N-	47	103	150
O+	55	95	150
O-	44	106	150
NO+	52	98	150
NO-	47	103	150

<sup>1</sup>Men and women are Intake Classes #43 and #44, respectively, as listed in Chapter 14. Symbols are defined in the text (Chapter 12).

assigned to the nursing program had principal diagnoses of cardiovascular-renal disease with indicators of coexisting major chronic conditions more often than those not assigned to the program. In the area of social characteristics, those assigned for nursing services were more likely to be living with a spouse or child. Patients who were observed regularly did not differ from those who were not observed regularly in respect to any of the 70 intake characteristics. In the search for differences between patients classified by interaction between the nursing program and observation process, the interaction group had fewer patients with hypertension and fewer who lived alone. Whereas nonrandomized studies are subject to the criticism that the outcome may be a result of

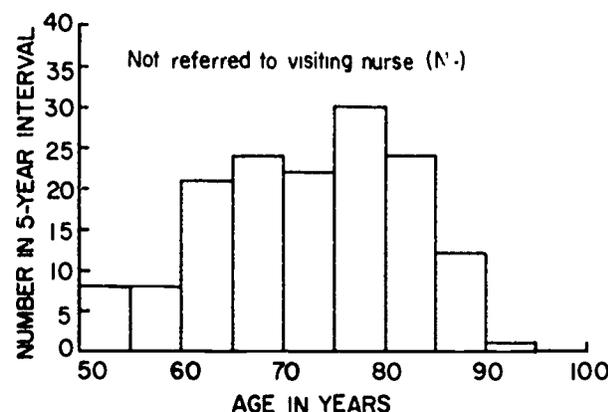
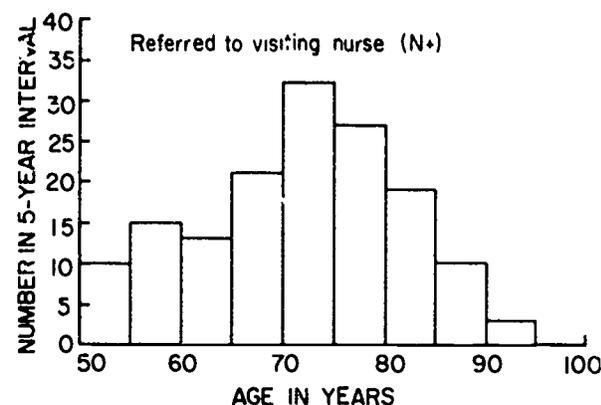


Figure XII-1. Age Distribution on Admission into Study

differences in intake characteristics, our study is not subject to this criticism.

*Validity of the Experimental Groups*

The fact that patients were assigned to the four primary groups (N-O-, N+O+, N+O-, N-O+) by the randomization process did not necessarily mean that they would participate fully as assigned. A patient assigned to the N-O+ group, for example, was not necessarily deprived of the nursing program, while one assigned to the N+O+ group might not participate fully in the nursing program and observation process. It was, thus, necessary to examine the extent to which those patients assigned to the N+ experimental group actually participated in the treatment program and, equally important, the extent to

Table 12.3—Expected and Actual Percentages of Significant Chi-Square Tests for Intake Class Distributions Among Study Groups<sup>1</sup>

	Percentages			
“Expected”	5	10	20	30
“Actual” for Primary Groups	0	7	13	21
“Actual” for Experimental Groups				
N+ against N-	4	10	17	30
O+ against O-	0	4	14	29
NO+ against NO-	3	13	23	34

<sup>1</sup>Expected percentages are the proportions of statistically significant results which correspond in theory to individual chi-square values. Actual percentages are the proportions of significant results which were observed at these chi-square values. Symbols are defined in the text (Chapter 12).

which those assigned to the N- group did not. It was, similarly, necessary to examine the extent of participation in the observation process for the O+ and O- experimental groups.

A detailed description of patient participation in the nursing program was summarized in Tables 4.1, 4.2, and 4.3 of Chapter 4, where we concluded that (1) the number of people in the nursed group who received nurse visits was much greater than the number in the non-nursed group; (2) of those receiving visits, the people in the nursed group received more visits per person than those in the non-nursed group; and (3) the nursing care follow-up was more sustained in the nursed group than in the non-nursed group. The large difference in visits was also demonstrated in Figures IV-1 through IV-6. Finally, in a separate statistical analysis, we demonstrated that, throughout the study, every intake class for the N+ group received significantly more visits than the corresponding intake class for the N- group.

The 300 patients in the study had access to private nurses, companions, relatives, and other persons giving care, as well as to the VNA. Data on non-VNA assistance was obtained in interviews, and we found no significant differences between nursed and non-nursed experimental

groups or subgroups (intake classes) with regard to non-VNA assistance. Such additional care did not, therefore, affect the validity of the experimental groups.

In view of the above discussion, there are no qualms about the validity of the N+ and N- experimental groups. The N+ and N- groups can be correctly said to “receive” and “not receive” the treatment program, respectively.

In Chapter 5, we examined in detail the extent of participation in the observation process for the O+ and O- experimental groups. Tables 5.1 and 5.2 in that chapter demonstrate the marked success with which the observation schedule was accomplished for patients in the O+ group (assigned to quarterly observations) and O- group (assigned only to intake and terminal observations.) Although certain interview forms had greater completion rates than others, successful completion of the type described in Chapter 5 was the rule. In no case did we completely lose a patient to follow-up. The few patients who moved out of the state were contacted through close relatives or friends, and their local physicians were contacted to assist with required evaluations. More than 93 per cent of the evaluations were achieved within nine days after the dates they were due.

We designed the randomization process to insure that each interviewer was assigned the same number of patients within each primary group and at random. Individual observer effects were, thus, distributed equally among the primary and experimental groups, and were more surely related to the observation process than to the individual observers. The only deviation was for reasons of illness of observers or because of vacations. Illness or vacations required substitute observers, none of whom was a regularly scheduled observer. Substitutions comprised 4 per cent of intake evaluations and less thereafter. The disparity at intake was larger, since the contents of the observer-assignment envelopes were unknown at that time, and planning with respect to vacations could not be foreseen nor effected.

In summary, the above discussion confirms the validity of the O+ and O- experimental

groups. We can reasonably interpret differences between these groups as related to the observation process.

#### *Outcome Classes*

Classes were defined to evaluate the consequences of the nursing program. These classes were entitled "outcome classes" and were expressed in terms of function (physical, psychological, and social), injury death, and use of services. We present detailed definitions of the outcome classes in Chapter 14. Whenever possible, outcome classes were defined to measure a change in the patient from the time of entry into the study. For example, Outcome Class #3 at six months included patients who deteriorated in activities of daily living during the six months period after entering the study. This technique of treating each patient as his own control was conceptually equivalent to increasing the homogeneity of intake classes, as well as of primary and experimental groups.

Though we dichotomized the outcome classes (e.g., dead or alive, deteriorated or not, admitted to a nursing home or not), there were occasions when membership in an outcome class could not be determined due to missing or incomplete information. In other instances, patients who died were excluded by definition for conceptual reasons as in the case of Outcome Class #4, "patients who deteriorated in walking." In yet other instances, information was unknown because the study was not designed to collect it, as in the case of quarterly interval information for non-observed patients or in the case of information about social interaction which was designed to be collected semiannually and not quarterly. As discussed later in this chapter and in Chapter 5, the completeness of the data was excellent; and we made careful interpretations which took into account the various types of unknowns. With respect to death, the design of the study was to analyze the occurrence of death as one type of outcome and to exclude those who died in analyses of other outcomes, rather than to diffuse the interpretations about such outcomes by including deaths. Users of the data can, thus, clearly understand the bases for our interpretations.

In order to reduce the number of unknowns for the various outcome classes at the terminal point of the study, 24 month data obtained by observers assigned to quarterly evaluations were substituted in the occasional instances where 24 month data could not be obtained by randomly assigned new observers. We compared the two types of data, before pooling, to see how closely they agreed (Table 12.4). Agreement was good and served as an indication of the reproducibility of the observation process, recognizing also that the following factors contributed to the variability of such data. Though both sets of data were obtained at 24 months, the pairs of evaluations did not take place at exactly the same time. The pairs of evaluations were, furthermore, conducted by different interviewers; and patient recall was not constant.

Statistical tests were used to check the process of random assignment of patients to the primary and experimental groups, by which process one expects to balance out such extraneous factors as age, sex, and degree of illness between the study groups. Other uses of statistical tests were to check the validity of the study design, to test associations which might have been related only indirectly to the study design, and to discover the nursing program effects on outcomes. For these purposes, we constructed contingency tables as comparisons between the

Table 12.4--Agreement Between Two Sets of 24 Month Data Obtained by Separate Interviewers

Outcome class <sup>1</sup>	Per cent agreement
#3	91
#4	93
#5	93
#12	98
#13	100
#14	91
#15	87
#16	88
#17	99
#23	95
#24	87
#25	87

<sup>1</sup>Outcome Classes are defined in Chapter 14.

various study groups. The test generally used to determine whether there was a statistically significant difference was the chi-square test. No test of significance was done on a 2 by 2 table if any row or column totalled less than 4, or if  $n$  was less than 13. We applied Fisher's exact method for calculating probability if  $n$  was less than 20, or if  $n$  was less than 40 and the expected value for any of the four cells of the table was less than 5. We used the chi-square test in all other instances. All tests were two-tailed. In an experimental design such as the one used here, statistical analyses do not determine with complete certainty the presence or absence of an experimental effect on any particular outcome. The degree of uncertainty may, however, be calculated and expressed precisely in terms of probabilities. In the present study, we considered a result as statistically significant if the relevant statistical test was significant at the 5 per cent level ( $P < 0.05$ ). This means that, in the absence of a nursing effect on a particular outcome, we would incorrectly state that there was a nursing effect 5 times out of 100 in repeated performances of the experiment under similar circumstances. Recognizing that, in examining a very large number of tests, some differences are likely to occur by chance, we assessed and described the consistency of differences. We also compared the most frequently encountered outcomes (any outcome which was significant for at least five percent of the study's Intake Classes) with less frequent outcomes, as reported in Chapter 7.

When the chi-square value for a given contingency table is large enough to be statistically significant ( $P < 0.05$ ), one of several interpretations is usually given: (1) the P-value is significant because of a causal relationship between the factors compared in the table; (2) the P-value is significant because of an association (not necessarily causal) between the factors compared in the table; or (3) the P-value is significant for reasons due solely to chance. The appropriate interpretation or valid conclusion that can be inferred from a P-value depends most strongly on the design and execution of the study: Several different ways of obtaining the data were used in the present study, and it is

crucial to the interpretation of the study's results to understand them. Brief examples are in order, and for this purpose, two models of tables will be considered.

Case 1: The model table is

Primary Group	Admitted to a nursing home during the study (Outcome Class #18)	
	Yes	No
N+O-	<i>a</i>	<i>b</i>
N-O-	<i>c</i>	<i>d</i>

In this case, extraneous factors which influence entry into a nursing home are expected to be distributed equally between the primary groups because of the randomization process. The observer effect is absent; therefore, any unusual distribution of the numbers (*a*, *b*, *c*, *d*) in the table may be attributed to the effect of the nursing program. A significant chi-square value is validly interpreted here as evidence of a causal relationship between the nursing program and subsequent nursing home admission, and the direction of the causal relationship may either be negative or positive (fewer or more admissions, respectively). By definition, a significant chi-square value will occur 5 per cent of the time, by chance, in the absence of a nursing program effect on outcome. On the other hand, a nonsignificant chi-square value may occur even when there is a causal relationship. This may be due to chance, to too small a sample size, to relative insensitivity of the outcome measures, to a relatively weak causal relationship, or to some combination of these. The probability of realizing a nonsignificant chi-square value in the presence of an actual causal relationship cannot be calculated because of the lack of precise knowledge of the extent of the causal relationship. Tables similar to the model table for Case 1 are interpreted in the same manner.

Case 2: The model table is

Experimental subgroup (Intake Class #43)	Admitted to a nursing home (Outcome Class #18)	
	Yes	No
N+ males	<i>a</i>	<i>b</i>
N- males	<i>c</i>	<i>d</i>

This case differs from the preceding one in two important respects. First, only males are considered, and patients were not randomly assigned to experimental groups according to sex. Second, males of all four primary groups are considered, and the presence of observers in two of the groups could lead to observer or interaction biases. As stated earlier in this chapter, the process of random assignment guarantees that extraneous factors such as being a male are, on the average, equally distributed between experimental groups. Within the limits of statistical inference, therefore, interpretations of causal relationships are valid. With respect to possible observer or interaction biases, the present study was designed to identify such biases. When found, we took such biases into account in order to make valid interpretations.

We scheduled outcome evaluations at eleven times during the two years of the study as described in detail in Chapter 2. The N, O, and NO effects were calculated for each of the 1988 combinations of the 71 intake and 28 outcome classes at the end of the study. As we explained in Chapter 10, dates of death, injury, admission to nursing homes, and admission to hospitals were identified for all 300 patients; thus, interval treatment effects during the two years could be determined exactly with respect to these outcomes, and without bias by the observation process. For other outcomes, the only interval effect that could be determined was a nursing effect in the presence of observers (N+O+ against N-O+). This effect, it will be recalled, could have been biased by the observation process; and we discuss its analysis and interpretation in detail in other parts of this chapter and in Chapter 10. In every case where an interaction effect could be determined and was found to be statistically significant, the unbiased nursing program effect (N+O- against N-O-) was calculated and substituted for the N effect. In every case where interaction effects could not be determined exactly, nursing program effects were examined in the light of the interaction effects which were identified at the end of the study; and limited interpretations about unbiased nursing program effects were made on a defined and rational basis.

As an extensive example of analysis and interpretation let us consider experimental effects in terms of admission to a hospital (outcome Class # 19) during the first year of the study for patients who had not recently retired, ceased homemaking, or been widowed (Intake Class # 69). The data and results of statistical analyses are presented in Table 12.5. Chi-square test results reveal statistically significant N and NO effects at the 5 per cent probability level and no significant O effect. The direction of the N effect is positive (more patients admitted to hospitals in the presence of the nursing program), while the direction of the NO effect is negative (fewer patients admitted in the presence of interaction). If there were no interaction between the nursing program and observation process, the comparison of N+ against N- would yield an unbiased measure of the nursing program effect. Since an interaction effect is present, the nursing program effect represented by the N+ against N- comparison is biased by the presence of the observation process; and the best unbiased comparison for the nursing program effect is N+O- against N-O-. In Table 12.5, this unbiased effect is 33 per cent and is statistically significant at the 5 per cent probability level. Its direction is positive, that is, more patients were admitted in the presence of the nursing program than in its absence. We conclude that there was a causal relationship between the presence of the nursing program and admission to hospitals during the first year of the study.

We can define the effects in the preceding example precisely in terms of percentage differences between the comparison groups for particular outcomes. The statistically significant effects are 19 per cent for the N effect, -16 per cent for the interaction effect, and 33 per cent for the N(O-) effect. As discussed previously, the N(O-) effect (33 per cent) is the best unbiased measure of the nursing program effect in this example. The effects in terms of percentage differences are quantitative estimates of the study's consequences, representing proportional changes which would be expected for surviving patients of this type as a result of the service program which was applied. Such quantitative estimates were summarized in Chapter 11.

Table 12.5—Experimental Effects on Hospitalization During the First Year of the Study in Socially Nondeprived Patients<sup>1</sup>

Study Group	Hospitalized		Experimental effect	Chi-square value
	Yes	No		
	(number of persons)			
N+	48	47	N = 19%	6.67 <sup>2</sup>
N-	29	62		
O+	33	54	O = -6%	0.81
O-	44	55		
NO+	34	66	NO = -16%	4.88 <sup>2</sup>
NO-	43	43		
N+O+	19	29	N(O+) = 4%	0.12
N-O+	14	25		
N+O-	29	18	N(O-) = 33%	10.79 <sup>2</sup>
N-O-	15	37		

<sup>1</sup>Socially nondeprived patients are those who had not recently retired, ceased homemaking, or been widowed (Intake Class #69 in Chapter 14). Hospitalized is the Outcome Class #19 in Chapter 14. Symbols for the study groups and experimental effects are defined in Chapter 12.

<sup>2</sup>Value is statistically significant at the 0.01 level.

### **CHAPTER XIII. EVALUATION SCHEDULE, STUDY FORMS AND SUPPLEMENTARY DEFINITIONS**

This chapter includes: the chronological schedule of evaluations for the study; all forms used to accumulate information; and supplementary definitions to the material presented in Chapter 5, *Interviewing and Measures*. The chronological schedule appears as Figure XIII-1, which lists the title of each form and the times when each was completed. The study forms which appear next are worded in enough detail to minimize the need for additional definitions; however, observers needed access to additional written material about definitions and procedures. Such additional information was made available to observers in the form of a guide. The

guide included the particular interview instructions for this study, the content of the observations, and the published sources of the measures described in Chapter 5. The guide, also, included the material in the present chapter. Definitions and procedures that appear in published literature are not reproduced in full detail, since this would be unnecessary duplication. For those measures, however, that are not adequately described in published literature, definitions and descriptions of procedures are presented as the last section of this chapter, "Supplementary Definitions".



Effects of Continued Care

Interview Schedule

Study No. \_\_\_\_\_ Months of Follow \_\_\_\_\_ Reference Date \_\_\_\_\_ Form No. A-1

	Date Due	Forms due (cross off when completed)												
Admission														
Post discharge														
1st quarter														
2nd quarter														
3rd quarter														
4th quarter														
5th quarter														
6th quarter														
7th quarter														
8th quarter														

Additional Forms

Form number														
Dates due														

Patient's Name \_\_\_\_\_ Address \_\_\_\_\_ Phone \_\_\_\_\_

Interviewer \_\_\_\_\_

Admission Socioeconomic Evaluation

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of admission into study \_\_\_\_\_, Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

1. Birthday (month-day-year) \_\_\_\_\_

2. Sex (check): Male \_\_\_\_\_ Female \_\_\_\_\_ Color (check): White \_\_\_\_\_ Non-white \_\_\_\_\_

3. Occupation

If (he) (she) worked during the past 10 years describe the job or business held last week, if any, by answering the following questions. If no job or business last week, give the information for the last job or business during the 10 year interval.

a. For whom did he work? \_\_\_\_\_  
(Write name of company, business, organization or other employer)

b. What kind of business or industry was this? \_\_\_\_\_  
(examples: poultry hatchery, county junior high school, auto assembly plant, radio and TV service, retail supermarket, highway construction)

c. What kind of work was he doing? \_\_\_\_\_  
(examples: truck driver, 8th grade English teacher, paint sprayer, repairs TV sets, grocery checker, civil engineer)

d. Class of worker (check one)?

Employee of a private company, business or individual for wages, salary, or commissions \_\_\_\_\_

Government employee (Federal, State, or local) \_\_\_\_\_

Self-employed in own business, professional practice or farm \_\_\_\_\_

Working without pay in a family business or farm \_\_\_\_\_

Other (specify) \_\_\_\_\_

Admission Socioeconomic Evaluation (continued)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

4. Circle the trade class that applies to usual occupation.  
(Usual occupation is the kind of work patient has done in the past and would be doing now except for age, illness, or injury.)
- a. Higher executives, large proprietors (over \$100,000), and major professionals.
  - b. Business managers (large concern), proprietors (medium businesses \$35,000 to \$100,000), lesser professionals.
  - c. Administrative personnel, proprietors (small businesses \$6,000 to \$35,000), semi-professionals, farm owners (\$20,000 to \$55,000).
  - d. Clerical and sales workers, technicians, proprietors (little businesses, \$3,000 to \$6,000), farm owners (\$10,000 to \$20,000).
  - e. Skilled manual employees, small farm owners (under \$10,000).
  - f. Machine operators and semi-skilled employees.
  - g. Unskilled employees, sharecroppers.
5. Education attainment (check appropriate column and circle highest grade completed).
- |   |  |
|---|--|
| <input type="checkbox"/> O K 1 2 3 4 5 6 7 8                                      | <input type="checkbox"/> College <u>1</u> <u>2</u> <u>3</u> <u>4</u> Grad. Prof. Postgrad. |
| <input type="checkbox"/> H.S. 1 2 3 4   | (Indicate highest degree awarded _____)  |
| <input type="checkbox"/> If foreign educated approximate equivalent in U.S. _____ | <input type="checkbox"/> Unknown (give best approx.)                                       |
6. Place of birth: In what state, U.S. possession, or foreign country was patient born? \_\_\_\_\_
7. Date of last employment (or, if housewife, date when patient discontinued management of her own home) \_\_\_\_\_
8. If patient is a widow or widower, what was the date of death of spouse?  
\_\_\_\_\_

Social Interaction

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

Nature of evaluation (check one):

Admission \_\_\_\_\_ 6 mo. \_\_\_\_\_ 1 yr. \_\_\_\_\_ 1 yr. 6 mo. \_\_\_\_\_ 2 yrs. \_\_\_\_\_

Number of social contacts in or out of the home:

1. How many living children do you have?\* \_\_\_\_\_ daughter(s) \_\_\_\_\_ son(s) \_\_\_\_\_

- a. How often did you get together with them? \_\_\_\_\_
- Daily \_\_\_\_\_
  - Twice or more weekly \_\_\_\_\_
  - Weekly \_\_\_\_\_
  - Every 2 to 3 weeks \_\_\_\_\_
  - Monthly \_\_\_\_\_
  - No regular visits \_\_\_\_\_

b. Other contacts with them (i.e., letter, phone, etc.)?

Specify: \_\_\_\_\_

2. Frequency of interaction with relatives (i.e., brothers, sisters, grandchildren, in-laws, nephews, nieces).

- Daily \_\_\_\_\_
- Twice or more weekly \_\_\_\_\_
- Weekly \_\_\_\_\_
- Every 2 to 3 weeks \_\_\_\_\_
- Monthly \_\_\_\_\_
- No regular visits \_\_\_\_\_

3. Frequency of interaction with friends.

- Daily \_\_\_\_\_
- Twice or more weekly \_\_\_\_\_
- Weekly \_\_\_\_\_
- Every 2 to 3 weeks \_\_\_\_\_
- Monthly \_\_\_\_\_
- No regular visits \_\_\_\_\_

4. Frequency of interaction with neighbors.

- Daily \_\_\_\_\_
- Twice or more weekly \_\_\_\_\_
- Weekly \_\_\_\_\_
- Every 2 to 3 weeks \_\_\_\_\_
- Monthly \_\_\_\_\_
- No regular visits \_\_\_\_\_

\*Indicate if respondent voluntarily reports deceased children:

Number \_\_\_\_\_ Estimated date(s) \_\_\_\_\_

Social Interaction (continued)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

5. Now, how about the people you saw for special reasons (for example, the banker or financial adviser, guardian, bus driver, mailman, salesman, newsboy, waiter, etc.) — about how many of these did you see regularly?

Specify: \_\_\_\_\_

6. How many other social activities did you attend (i.e., church, clubs, etc.)?

Specify: \_\_\_\_\_

7. In the course of a day, you talked to about how many people? (including phone calls)

\_\_\_\_\_

Is this more than, less than, or about the same as when you were younger, say for example, when you were 45?

Social Interaction  
(Terminal Evaluation)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

Number of social contacts in or out of the home:

1. How many living children do you have? \_\_\_\_\_ daughter(s) \_\_\_\_\_ son(s) \_\_\_\_\_

a. How often did you get together with them? \_\_\_\_\_

Daily \_\_\_\_\_  
Twice or more weekly \_\_\_\_\_  
Weekly \_\_\_\_\_  
Every 2 to 3 weeks \_\_\_\_\_  
Monthly \_\_\_\_\_  
No regular visits \_\_\_\_\_

b. Does the patient have any other contact (indirect) with the children such as by letter, phone, other message, etc.?

(yes or no) \_\_\_\_\_

c. Where does the child live whom the patient sees most often?

With the patient \_\_\_\_\_  
In the neighborhood \_\_\_\_\_  
Outside of the neighborhood \_\_\_\_\_

2. Frequency of interaction with relatives (i.e., brothers, sisters, grandchildren, in-laws, nephews, nieces).

Daily \_\_\_\_\_  
Twice or more weekly \_\_\_\_\_  
Weekly \_\_\_\_\_  
Every 2 to 3 weeks \_\_\_\_\_  
Monthly \_\_\_\_\_  
No regular visits \_\_\_\_\_

3. Interaction with friends (single most frequent interaction).

Daily \_\_\_\_\_  
Twice or more weekly \_\_\_\_\_  
Weekly \_\_\_\_\_  
Every 2 to 3 weeks \_\_\_\_\_  
Monthly \_\_\_\_\_  
No regular visits \_\_\_\_\_

Does this friend live-

In the neighborhood \_\_\_\_\_  
Out of the neighborhood \_\_\_\_\_

Social Interaction (continued)

(Terminal Evaluation)

Name \_\_\_\_\_

Study No. \_\_\_\_\_

4. Interaction with friends (second most frequent interaction).

- Daily \_\_\_\_\_
- Twice or more weekly \_\_\_\_\_
- Weekly \_\_\_\_\_
- Every 2 to 3 weeks \_\_\_\_\_
- Monthly \_\_\_\_\_
- No regular visits \_\_\_\_\_

Does this friend live-

- In the neighborhood \_\_\_\_\_
- Out of the neighborhood \_\_\_\_\_

5. Now, how about the people you saw for special reasons (for example, the banker or financial adviser, guardian, bus driver, mailman, salesman, newsboy, waiter, etc.) - about how many of these did you see regularly?

Specify: \_\_\_\_\_  
\_\_\_\_\_

6. How many other social activities did you attend (i.e., church, clubs, etc.)?

Specify: \_\_\_\_\_

7. In the course of a day, you talked to about how many people? (including phone calls)

\_\_\_\_\_

Is this more than, less than, or about the same as when you were younger, say for example, when you were 45?

Social and Economic Function

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

Nature of evaluation (check one):

Admission \_\_\_\_\_ 3 mo. \_\_\_\_\_ 6 mo. \_\_\_\_\_ 9 mo. \_\_\_\_\_ 1 yr. \_\_\_\_\_

Post Discharge \_\_\_\_\_ 1 yr. 3 mo. \_\_\_\_\_ 1 yr. 6 mo. \_\_\_\_\_ 1 yr. 9 mo. \_\_\_\_\_ 2 yrs. \_\_\_\_\_

1. Residence address (complete mailing, including postal zone): \_\_\_\_\_  
 \_\_\_\_\_ Phone No. \_\_\_\_\_

2. Nature of residence (check one):

Single home \_\_\_\_\_ Hotel \_\_\_\_\_ Nursing \_\_\_\_\_  
 Double home \_\_\_\_\_ Boarding \_\_\_\_\_ Hospital \_\_\_\_\_  
 Apartment \_\_\_\_\_ Custodial \_\_\_\_\_ Other (specify) \_\_\_\_\_

3. Is patient legally designated owner of his residence (check):

Yes \_\_\_\_\_ No \_\_\_\_\_

4. Is patient gainfully employed 1 or more hours per week (yes or no)? \_\_\_\_\_  
 (Including even such employment as baby sitting or other employment in the home.)

If "yes" indicate nature and hours per week of employment \_\_\_\_\_

If unemployed since last visit, indicate date \_\_\_\_\_

5. Check the sources of funds used for food, clothing, shelter, and medical care:

Parents, children, siblings, their progeny or spouses	Aid for the aged, social agencies, state, city, or county	Social Security	Private industrial plans (retirement or insurance), savings, salary, stocks or bonds (pt. or spouse)	Other (specify)

6. Marital status (check): Married \_\_\_\_\_ Never married \_\_\_\_\_ Divorced \_\_\_\_\_  
 Separated \_\_\_\_\_ Widow(er) \_\_\_\_\_

If spouse deceased since last visit, specify date \_\_\_\_\_



Social and Economic Function (continued)

Name \_\_\_\_\_

Study No. \_\_\_\_\_

7. Household composition:

	Relationship to patient	Age	Sex	Indicate specific kinds of medical housekeeping, or supervisory assistance given to patient
Head →				

Notice: Omit the next two items from the Intake Interview only.

8. Has anyone close to you passed away since I talked with you (i.e., children, grandchildren, friends and neighbors, other relatives, and service personnel)?

No \_\_\_\_\_ Yes \_\_\_\_\_ If "yes," who? \_\_\_\_\_

9. Has anyone close to you moved since I talked with you, so that the inconvenience of travel prevents you from getting together with them now?

No \_\_\_\_\_ Yes \_\_\_\_\_ If "yes," who? \_\_\_\_\_

Social and Economic Function  
(Terminal Evaluation)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

1. Residence address (complete mailing, including postal zone)  
\_\_\_\_\_ Phone No. \_\_\_\_\_

2. Nature of residence (check one):

Single home _____	Hotel _____	Nursing _____
Double home _____	Boarding _____	Hospital _____
Apartment _____	Custodial _____	Other (specify) _____

3. Is patient legally designated owner of his residence (check):  
Yes \_\_\_\_\_ No \_\_\_\_\_

4. Is patient gainfully employed 1 or more hours per week (yes or no)? \_\_\_\_\_  
(Including even such employment as baby sitting or other employment in the home and consider employment as activity which is functionally involved in procuring income.)

a. If "yes" indicate nature and hours per week of employment \_\_\_\_\_

b. Indicate date patient retired from employment \_\_\_\_\_

c. Indicate date patient ceased being home maker \_\_\_\_\_

5. Check the sources of funds used for food, clothing, shelter, and medical care:

Parents, children, siblings, their progeny or spouses	Aid for the aged, social agencies, state, city, or county	Social Security	Private industrial plans (retirement or insurance), savings, salary, stocks or bonds (pt. or spouse)	Other (specify)

6. Marital status (check): Married \_\_\_\_\_ Never married \_\_\_\_\_ Divorced \_\_\_\_\_  
Separated \_\_\_\_\_ Widow(er) \_\_\_\_\_

If spouse deceased, specify date \_\_\_\_\_



Social and Economic Function (continued)

(Terminal Evaluation)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

7. Household composition:

	Relationship to patient	Age	Sex	Indicate specific kinds of medical housekeeping, or supervisory assistance given to patient
Head →				

Activities of Daily Living

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

Nature of evaluation (check one):

Admission \_\_\_\_\_ 3 mo. \_\_\_\_\_ 6 mo. \_\_\_\_\_ 9 mo. \_\_\_\_\_ 1 yr. \_\_\_\_\_  
 Post discharge \_\_\_\_\_ 1 yr. 3 mo. \_\_\_\_\_ 1 yr. 6 mo. \_\_\_\_\_ 1 yr. 9 mo. \_\_\_\_\_ 2 yrs. \_\_\_\_\_

For each area of functioning listed below, check description that applies. (The word "assistance" means supervision, direction or personal assistance.)

Bathing - either sponge bath, tub bath, or shower -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Receives no assistance (gets in and out of tub by self if tub is usual means of bathing)	Receives assistance in bathing only one part of the body (such as back or a leg)	Receives assistance in bathing more than one part of the body (or not bathed)

Dressing - gets clothes from closets and drawers - including underclothes, outer garments and using fasteners (including braces if worn) -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Gets clothes and gets completely dressed without assistance	Gets clothes and gets dressed without assistance except for assistance in tying shoes	Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed

Toileting - going to the "toilet room" for bowel and urine elimination; cleaning self after elimination, and arranging clothes -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Goes to "toilet room," cleans self, and arranges clothes without assistance (may use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in AM)	Receives assistance in going to "toilet room" or in cleansing self or in arranging clothes after elimination or in use of night bedpan or commode	Doesn't go to room termed "toilet" for the elimination process

Transfer -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as cane or walker)	Moves in or out of bed or chair with assistance	Doesn't get out of bed

Effects of Continued Care

Activities of Daily Living (continued)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

For each area of functioning listed below, check description that applies. (The word "assistance" means supervision, direction or personal assistance.)

Continence -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Controls urination and bowel movement completely by self	Has occasional "accidents"	Supervision helps keep urine or bowel control; catheter is used, or is incontinent

Feeding -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Feeds self without assistance	Feeds self except for getting assistance in cutting meat or buttering bread	Receives assistance in feeding or is fed partly or completely by using tubes or I.V. fluids

Walking -

1 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Walks on level without assistance	Walks without assistance but uses two points for mechanical support such as crutches, a walker or two canes (or wears a brace)	Walks with assistance
2 <input type="checkbox"/>		5 <input type="checkbox"/>
Walks without assistance but uses single, straight cane		Uses wheelchair only
		6 <input type="checkbox"/>
		Not walking or using wheelchair

House-confinement -

1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
Has been outside of residence on 3 or more days during past 2 weeks	Has been outside of residence on only 1 or 2 days during past 2 weeks	Has not been outside of residence in past 2 weeks

Specify the person or persons giving assistance in each dependent function:

	1	2	3	4
	Spouse	Parents, children, siblings, or progeny or spouse of any	Attendants, companions, housekeepers, institutional staff, friends, visiting nurse	Other (specify)
Bathing				
Dressing				
Going to toilet				
Transfer				
Continence				
Feeding				
Walking				

Medical Care

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

Nature of evaluation (check one):

Post Discharge \_\_\_\_\_ 3 mo. \_\_\_\_\_ 6 mo. \_\_\_\_\_ 9 mo. \_\_\_\_\_ 1 yr. \_\_\_\_\_

1 yr. 3 mo. \_\_\_\_\_ 1 yr. 6 mo. \_\_\_\_\_ 1 yr. 9 mo. \_\_\_\_\_ 2 yrs. \_\_\_\_\_

1. a. Since last interview has the patient been in a hospital, nursing home, or other custodial residence? Yes \_\_\_\_\_ No \_\_\_\_\_

b. If "yes," list:

Hospital	Nursing Home or Custodial Residence	Admission Date (mo.-day-yr.)	Discharge Date (mo.-day-yr.)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

2. a. Does the patient have hospital insurance? Yes \_\_\_\_\_ No \_\_\_\_\_

b. If "yes," enter the name of the company \_\_\_\_\_

3. a. Since last interview, has the patient made a permanent change in residence?  
Yes \_\_\_\_\_ No \_\_\_\_\_

b. If "yes," also complete both forms A-5 and A-7 for every permanent move during the interval.

4.\* a. Last week or the week before, did a doctor examine or talk to the patient?  
Yes \_\_\_\_\_ No \_\_\_\_\_ (if "no" skip to Question 5).

b. How many times during the past 2 weeks? \_\_\_\_\_

c. Where did the patient talk with the doctor?

Times	Home	Dr.'s Office	Hospital Clinic	Hospital	Telephone
_____	_____	_____	_____	_____	_____

5.\* a. How long has it been since a doctor last examined or talked to the patient?  
weeks \_\_\_\_\_ months \_\_\_\_\_

b. Where did the contact take place?

Home	Dr.'s Office	Hospital Clinic	Hospital	Telephone
_____	_____	_____	_____	_____

\*Questions 4 through 7 refer to direct contacts. Indirect contacts should be described in REMARKS.

Effects of Continued Care

Medical Care (continued)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

5.\* c. Who is the patient's regular doctor? Name \_\_\_\_\_

Address \_\_\_\_\_

6.\* a. Last week, or the week before, did a nurse have professional contact with the patient? Yes \_\_\_\_\_ No \_\_\_\_\_ (if "no," skip to Question 7)

b. How many times during the past 2 weeks? \_\_\_\_\_

c. What kind of nurses were they?

	Visiting Nurse	County Nurse	Practical Nurse	Other (specify)
Times				

7.\* a. How long has it been since a nurse last had professional contact with the patient?  
\_\_\_\_\_ weeks \_\_\_\_\_ months

b. What kind of nurse was she?

	Visiting Nurse	County Nurse	Practical Nurse	Other (specify)

8. Since the last interview, has the patient received service from:

\_\_\_\_ Dentist, number of visits \_\_\_\_\_

\_\_\_\_ Optometrist, number of visits \_\_\_\_\_

\_\_\_\_ Chiropodist, number of visits \_\_\_\_\_

\_\_\_\_ Social worker, number of visits \_\_\_\_\_

\_\_\_\_ Physical therapist, number of visits \_\_\_\_\_

\*Questions 4 through 7 refer to direct contacts. Indirect contacts should be described in remarks.

REMARKS:

Medical Care  
(Terminal Evaluation)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

1. a. Since last interview has the patient been in a hospital, nursing home, or other custodial residence? Yes \_\_\_\_\_ No \_\_\_\_\_

b. If "yes," list:

Hospital	Nursing home or Custodial Residence	Admission Date (mo.-day-yr.)	Discharge Date (mo.-day-yr.)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

4.\* a. Last week or the week before, did a doctor examine or talk to the patient?  
Yes \_\_\_\_\_ No \_\_\_\_\_ (if "no" skip to Question 5)

b. How many times during the past 2 weeks? \_\_\_\_\_

c. Where did the patient talk with the doctor?

	Home	Dr.'s Office	Hospital Clinic	Hospital	Telephone
Times	_____	_____	_____	_____	_____

5.\* a. How long has it been since a doctor last examined or talked to the patient?  
\_\_\_\_\_ weeks \_\_\_\_\_ months

b. Where did the contact take place?

Home	Dr.'s Office	Hospital Clinic	Hospital	Telephone
_____	_____	_____	_____	_____

c. Who is the patient's regular doctor? Name \_\_\_\_\_

Address \_\_\_\_\_

6.\* a. Last week, or the week before, did a nurse have professional contact with the patient? Yes \_\_\_\_\_ No \_\_\_\_\_ (if "no," skip to Question 7)

b. How many times during the past 2 weeks? \_\_\_\_\_

c. What kind of nurses were they?

	Visiting Nurse	County Nurse	Practical Nurse	Other (specify)
Times	_____	_____	_____	_____

\*Refers to direct contacts. Indirect contacts should be described in remarks.

Effects of Continued Care

Medical Care (continued)

(Terminal Evaluation)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

7.\* a. How long has it been since a nurse last had professional contact with the patient?  
\_\_\_\_\_ weeks \_\_\_\_\_ months

b. What kind of nurse was she?

Visiting Nurse	County Nurse	Practical Nurse	Other (specify)
_____	_____	_____	_____

8. During the last 2 weeks has the patient received service from

\_\_\_\_\_ Dentist, number of visits \_\_\_\_\_

\_\_\_\_\_ Optometrist, number of visits \_\_\_\_\_

\_\_\_\_\_ Podiatrist, number of visits \_\_\_\_\_

\_\_\_\_\_ Social worker, number of visits \_\_\_\_\_

\_\_\_\_\_ Physical therapist, number of visits \_\_\_\_\_

9. In the past 3 months did the patient receive service? If so

\_\_\_\_\_ Dentist, number of visits \_\_\_\_\_

\_\_\_\_\_ Optometrist, number of visits \_\_\_\_\_

\_\_\_\_\_ Podiatrist, number of visits \_\_\_\_\_

\_\_\_\_\_ Social worker, number of visits \_\_\_\_\_

\_\_\_\_\_ Physical therapist, number of visits \_\_\_\_\_

10. a. Did a nurse take care of this patient in the home between discharge from Abington House (formerly Benjamin Rose Hospital) and this evaluation (terminal and/or death)? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," specify:

b. Did any other person come into the home to help with the care of the patient between discharge from Abington House (formerly Benjamin Rose Hospital) and this evaluation (terminal and/or death)? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," circle:

Relative - friend/neighbor - homemaker - part-time sitters

Others \_\_\_\_\_

\*Questions 4 through 7 refer to direct contacts. Indirect contacts should be described in REMARKS.

REMARKS:

Permanent Move

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

Nature of evaluation (check one):

3 mo. \_\_\_\_\_ 6 mo. \_\_\_\_\_ 9 mo. \_\_\_\_\_ 1 yr. \_\_\_\_\_  
 1 yr. 3 mo. \_\_\_\_\_ 1 yr. 6 mo. \_\_\_\_\_ 1 yr. 9 mo. \_\_\_\_\_ 2 yrs. \_\_\_\_\_

1. Date of permanent move (mo.-day-yr.) \_\_\_\_\_

2. Address of move (complete mailing, including postal zone) \_\_\_\_\_

3. Nature of residence (check one):

Single home \_\_\_\_\_ Hotel \_\_\_\_\_ Nursing \_\_\_\_\_  
 Double home \_\_\_\_\_ Boarding \_\_\_\_\_ Hospital \_\_\_\_\_  
 Apartment \_\_\_\_\_ Custodial \_\_\_\_\_ Other (specify) \_\_\_\_\_

4. Household composition:

	Relationship	Age	Sex	Indicate specific kinds of medical, housekeeping, or supervisory assistance given to patient
Head →				

5. Did you move because you were sick or needed care? (yes or no) \_\_\_\_\_

Effects of Continued Care

Physical Examination

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Physician \_\_\_\_\_

Nature of evaluation (check one): Entry \_\_\_\_\_ Terminal \_\_\_\_\_

History (check):

- |    | <u>Present</u>           | <u>Absent</u>            | <u>Unknown</u>           |   |
|----|--------------------------|--------------------------|--------------------------|---|
| 1. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 1. Chest pain for which an M.D. advised bed rest for 2 or more weeks (or history of diagnosis of coronary attack).  |
| 2. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 2. Distressful sensation relieved within a few minutes by nitroglycerin or rest<br>(occurring in precordium, any part of either upper extremity, left scapular region, angles of jaw, chin, or roof of mouth<br>&<br>precipitated by effort, acute emotional disturbance, a large meal, exposure to cold, or walking against the wind). |
| 3. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 3. Non-inflammatory polyarthritis (motion limited by pain in 2 or more joints) during past month.   |
| 4. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 4. Inflammatory polyarthritis during past month (pain and redness or swelling in 2 or more joints).   |

Current Examination (check):

- |    |  |                          |                          |  |
|----|--|--------------------------|--------------------------|--|
| 5. | <input type="checkbox"/>                               | <input type="checkbox"/> | <input type="checkbox"/> | 5. Any diastolic murmur in the mitral or aortic area in the absence of known congenital or syphilitic heart disease.                                       |
| 6. | <input type="checkbox"/>                               | <input type="checkbox"/> | <input type="checkbox"/> | 6. A Grade 3 or more mitral or aortic systolic murmur (Grade 1 is barely audible and sometimes not heard at first; Grade 2 is softly audible immediately). |
| 7. | Record blood pressure in left arm: start of exam _____ |                          |                          |  |
| 8. | end of exam _____                                      |                          |                          |  |

Current treatment (check):

- |     | <u>Yes</u>               | <u>No</u>                |  |
|-----|--------------------------|--------------------------|--|
| 9.  | <input type="checkbox"/> | <input type="checkbox"/> | 9. Digitalis or other cardiac glycoside.   |
| 10. | <input type="checkbox"/> | <input type="checkbox"/> | 10. Insulin or drug to reduce blood sugar. |

## Physical Examination (continued)

Range of Movement and Strength

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Anatomical Area	Test Instruction	Right				Left			
		Does not	Does		N.T.*	Does not	Does		N.T.*
			Without Resistance	Against Resistance			Without Resistance	Against Resistance	
Shoulder	Raise hand forward high above head								
	Put hand on back of head								
	Swing arm toward and away from midline at shoulder level								
Elbow	Bring hand to front of shoulder								
	With elbow at shoulder level straighten out arm								
Wrist	Wave hand side to side								
Fingers	Grasp small object with fingers								
	Extend fingers								
Thumb	Make tip of thumb touch tip of little finger								
	After touching fingertip extend thumb								
Knee	Kick foot into air								
Hip	Bring knee toward chest								
	Bring leg out to side								
	Return leg to center								
Ankle	Move foot from side to side								
	Bend foot up and down								

\*N.T. = Not Tested. Indicate reason whenever patient is not tested.

Effects of Continued Care

Physical Examination

(Terminal Evaluation)

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of Evaluation \_\_\_\_\_ Physician \_\_\_\_\_

History (check):

Present   Absent   Unknown

3.            3. Non-inflammatory polyarthrosis (motion limited by pain in 2 or more joints) during past month.

4.            4. Inflammatory polyarthrititis during past month (pain and redness or swelling in 2 or more joints).

7. Record blood pressure in left arm: start of exam \_\_\_\_\_  
end of exam \_\_\_\_\_

11. List each "fracture" or "broken bone" that patient has sustained during the past two years.

_____	_____
_____	_____
_____	_____

Physical Examination (continued)  
(Terminal Evaluation)

## Range of Movement and Strength

Name \_\_\_\_\_

Study No. \_\_\_\_\_

Anatomical Area	Test Instruction	Does not	Right			Left			
			Does		N.T.*	Does not	Does		N.T.*
			Without Resist- ance	Against Resist- ance			Without Resist- ance	Against Resist- ance	
Shoulder	Raise hand forward high above head								
	Put hand on back of head								
	Swing arm toward and away from midline at shoulder level								
Elbow	Bring hand to front of shoulder								
	With elbow at shoulder level straighten out arm								
Wrist	Wave hand side to side								
Fingers	Grasp small object with fingers								
	Extend fingers								
Thumb	Make tip of thumb touch tip of little finger								
	After touching fingertip extend thumb								
Knee	Kick foot into air								
Hip	Bring knee toward chest								
	Bring leg out to side								
	Return leg to center								
Ankle	Move foot from side to side								
	Bend foot up and down								

\*N.T. = Not Tested. Indicate reason whenever patient is not tested.

Effects of Continued Care

Laboratory Examinations

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Nature of evaluation (check one): Entry \_\_\_\_\_ Terminal \_\_\_\_\_

Date of test

\_\_\_\_\_ WEIGHT (in indoor clothing - doesn't include coats or suit coats - includes shoes) \_\_\_\_\_

\_\_\_\_\_ HEIGHT (with shoes) \_\_\_\_\_

\_\_\_\_\_ URINE PROTEIN (tested with Uristix) \_\_\_\_\_

\_\_\_\_\_ URINE SUGAR (tested with Uristix) \_\_\_\_\_

\_\_\_\_\_ BLOOD SUGAR (mg./100 cc.) \_\_\_\_\_

\_\_\_\_\_ TIME BLOOD DRAWN (may use designation 2 hr. p.c.) \_\_\_\_\_

\_\_\_\_\_ TIME LAST FOOD \_\_\_\_\_

\_\_\_\_\_ NEARPOINT "E" CHART VISION SCREENING \_\_\_\_\_

\_\_\_\_\_ C/T RATIO: (X-ray No. \_\_\_\_\_ ) \_\_\_\_\_

\_\_\_\_\_ BUN (mg./100 ml.) \_\_\_\_\_

EKG Findings

Patient's Name \_\_\_\_\_ Study No. \_\_\_\_\_

Physician \_\_\_\_\_ Date of EKG (mo.-day-yr.) \_\_\_\_\_

EKG FINDINGS (check)

PRESENT      ABSENT

- |       |       |  |
|-------|-------|--|
| _____ | _____ | Q of 0.04 seconds or more in AVL         |
| _____ | _____ | Q of 0.04 seconds or more in AVF         |
| _____ | _____ | QS in V <sub>3</sub>                     |
| _____ | _____ | QS in V <sub>4</sub>                     |
| _____ | _____ | QS in V <sub>5</sub>                     |
| _____ | _____ | QS in V <sub>6</sub>                     |
| _____ | _____ | Qr in V <sub>3</sub>                     |
| _____ | _____ | Qr in V <sub>4</sub>                     |
| _____ | _____ | Qr in V <sub>5</sub>                     |
| _____ | _____ | Qr in V <sub>6</sub>                     |
| _____ | _____ | QR in V <sub>3</sub>                     |
| _____ | _____ | QR in V <sub>4</sub>                     |
| _____ | _____ | QR in V <sub>5</sub>                     |
| _____ | _____ | QR in V <sub>6</sub>                     |
| _____ | _____ | QR greater than 25% in AVL               |
| _____ | _____ | QR greater than 25% in AVF               |
| _____ | _____ | Primary T changes in lead I              |
| _____ | _____ | Primary T changes in lead AVR            |
| _____ | _____ | Primary T changes in lead V <sub>3</sub> |
| _____ | _____ | Primary T changes in lead V <sub>4</sub> |
| _____ | _____ | Primary T changes in lead V <sub>5</sub> |
| _____ | _____ | Primary T changes in lead V <sub>6</sub> |
| _____ | _____ | Atrial fibrillation                      |
| _____ | _____ | Complete bundle branch block             |
| _____ | _____ | Second degree atrio-ventricular block    |
| _____ | _____ | Third degree atrio-ventricular block     |

Effects of Continued Care

Principal Diagnosis Leading to Admission

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Principal Diagnosis Leading to Admission  
(identify only one for each case)

- \_\_\_\_\_ arteriosclerotic heart disease (including myocardial infarction)
- \_\_\_\_\_ cerebral infarction
- \_\_\_\_\_ chronic brain syndrome
- \_\_\_\_\_ depressive, anxiety or psychoneurotic reaction
- \_\_\_\_\_ diabetes mellitus
- \_\_\_\_\_ exogenous obesity
- \_\_\_\_\_ fracture of femur
- \_\_\_\_\_ generalized arteriosclerosis
- \_\_\_\_\_ hypertensive cardiovascular disease
- \_\_\_\_\_ malignancy
- \_\_\_\_\_ osteoarthritis
- \_\_\_\_\_ paralysis agitans
- \_\_\_\_\_ pneumonia
- \_\_\_\_\_ rheumatoid arthritis
- \_\_\_\_\_ urinary tract infection
- \_\_\_\_\_ other (specify) \_\_\_\_\_

Was malignancy present (within 5 years before admission)? Yes \_\_\_ No \_\_\_

Did this patient sign out "against advice?" Yes \_\_\_ No \_\_\_



Coloured Progressive Matrices Test (Raven)

Scoring Form

Name \_\_\_\_\_ Sex \_\_\_\_\_ Age \_\_\_\_\_

School \_\_\_\_\_ Grade \_\_\_\_\_

Test Begun \_\_\_\_\_ Test Ended \_\_\_\_\_ Total Time \_\_\_\_\_

A		Ab		B	
1		1		1	
2		2		2	
3		3		3	
4		4		4	
5		5		5	
6		6		6	
7		7		7	
8		8		8	
9		9		9	
10		10		10	
11		11		11	
12		12		12	

Total Score \_\_\_\_\_

Percentile \_\_\_\_\_

Orientation and Mental Control Test

Patient's Name \_\_\_\_\_ Location \_\_\_\_\_

Study No. \_\_\_\_\_ Examiner \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Nature of evaluation (check one):  
Entry \_\_\_\_\_ Terminal \_\_\_\_\_

(Note: Take down patient's answers)

ORIENTATION FOR TIME

1. What year is it now? (Scored 1 or 0)
2. What month? (Scored 1 or 0)
3. What day? (Day of the week is OK) (Scored 1 or 0)
- Score \_\_\_\_\_

ORIENTATION FOR PLACE

1. What is this place we are in now? (Abington House, formerly Benjamin Rose = 2, Hospital = 1, other = 0)  
(My home = 2, if at home)
2. What city are we in now? (Scored 1 or 0)
3. What is your address (at home)? (Scored 1 or 0)
- Score \_\_\_\_\_

ORIENTATION FOR PERSON

1. What is your full name? (First & last = 2, first or last = 1, other = 0)
2. How old are you? (Scored 1 or 0)
3. Are you married? How many children? (Both correct = 2, one correct = 1, other = 0)
- Score \_\_\_\_\_

MENTAL CONTROL

1. Say the alphabet for me, like this "A, B, C, ...." (Within 30" no errors = 2, 30" one or two errors = 1, other = 0)
2. Count backwards from 20 all the way to 1, like this "20, 19, 18, ...." (30" no errors = 2, 30" one or two errors = 1, other = 0)
3. Count by threes starting with 1 until I tell you to stop. Like this, "1, 4, 7, .... add three each time." (45" up to 40 with no more than 1 error = 2, with 2 errors = 1, other = 0)
- Score \_\_\_\_\_

Note if patient is untestable (give reason):

Total Orientation and Mental Control  
SCORE \_\_\_\_\_ (Maximum = 18)

Effects of Continued Care

Data from Death Certificate

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Information from death certificate (if deceased):

18. CAUSE OF DEATH

Part I. Death was caused by:  
immediate cause (a) \_\_\_\_\_

Conditions, if any which gave rise to above cause (a), stating the underlying cause last. Due to (b) \_\_\_\_\_  
Due to (c) \_\_\_\_\_

Part II. Other significant conditions contributing to death but not related to the terminal disease condition given in Part I (a)

Date of Death:      Month      Day      Year      19. Was autopsy performed?  
Yes \_\_\_\_\_ No \_\_\_\_\_

Did death occur in hospital? (Yes or No) \_\_\_\_\_

Name of hospital, if "yes" \_\_\_\_\_

Did an M.D. attend the deceased on the day of death (Yes or No) \_\_\_\_\_

Socio-Medical History of Expired Patient

Name \_\_\_\_\_ Study No. \_\_\_\_\_

Date of evaluation \_\_\_\_\_ Interviewer \_\_\_\_\_

Informant \_\_\_\_\_ Relationship to patient \_\_\_\_\_

1. Indicate date patient retired from employment \_\_\_\_\_
2. Indicate date patient ceased being homemaker \_\_\_\_\_
3. If spouse deceased, specify date \_\_\_\_\_

4. a. Since last interview has the patient been in a hospital, nursing home, or other custodial residence? Yes \_\_\_\_\_ No \_\_\_\_\_

b. If "yes," list:

<u>Hospital</u>	<u>Nursing Home or Custodial Residence</u>	<u>Admission Date (mo.-day-yr.)</u>	<u>Discharge Date (mo.-day-yr.)</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

5. a. Did a nurse take care of this patient in the home between discharge from Abington House (formerly Benjamin Rose Hospital) and this evaluation? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," specify: \_\_\_\_\_

b. Did any other person come into the home to help with the care of the patient between discharge from Abington House (formerly Benjamin Rose Hospital) and this evaluation? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," circle:

Relative -- friend/neighbor -- homemaker -- part-time sitters  
Others \_\_\_\_\_

6. List each "fracture" or "broken bone" that patient sustained during the past two years.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Effects of Continued Care

Greater Cleveland Confidential Referral Form

Hospitals & Physicians and Public Health Nursing & Other Health Agencies

Use form to refer for continuity of care even if telephone contact is made. Complete in triplicate. Mail two copies to designated agency. One copy will be returned with a report for patient's record.

To: \_\_\_\_\_ Patient: \_\_\_\_\_ Hosp. No. \_\_\_\_\_  
O.P.D. No. \_\_\_\_\_  
Agency No. \_\_\_\_\_  
(Address) (Name)

Date of referral: \_\_\_\_\_ Tel. No. \_\_\_\_\_  
(Address in detail)

From: \_\_\_\_\_ Birth Date: \_\_\_\_\_ Sex: \_\_\_\_\_ S M W D Sep.

(Address) (Name of nearest relative or friend)

Tel. No. \_\_\_\_\_ Ext. \_\_\_\_\_ Hosp. Adm. Date: \_\_\_\_\_ Disch. Date: \_\_\_\_\_

(Person to contact) Next App't. Date: \_\_\_\_\_ Clinic \_\_\_\_\_  
(Name)

Physician's Diagnosis & Prognosis: Is patient aware of diagnosis & prognosis? \_\_\_\_\_  
Is family aware of diagnosis & prognosis? \_\_\_\_\_

Orders including Medication & Diet Instruction:

Date: \_\_\_\_\_ Physician's Signature: \_\_\_\_\_

Comments by Hospital Nurse:

Nurse's Signature: \_\_\_\_\_

Greater Cleveland Confidential Referral Form (continued)

Comments by Dietitian, Social Worker, Therapist (Occupational, Physical, Speech), Other:

Dates: \_\_\_\_\_ Signatures: \_\_\_\_\_  
\_\_\_\_\_

Comments by Public Health Nurse and/or Other Worker in Community Agency:

Dates: \_\_\_\_\_ Agency: \_\_\_\_\_ Signatures: \_\_\_\_\_  
\_\_\_\_\_ Address: \_\_\_\_\_ Tel. No. \_\_\_\_\_ Ext. \_\_\_\_\_  
\_\_\_\_\_

Authorization to Release Information:

I hereby authorize \_\_\_\_\_ to release such  
(Name of Clinic, Hospital and/or Physician)  
information in connection with this form as it, in its sole discretion, may deem proper.

Date: \_\_\_\_\_ Signature: \_\_\_\_\_  
(Patient or Legal Representative - Guardian if Minor)

Effects of Continued Care

V.N.A. Monthly Activity Record - Exercises

Patient's Name \_\_\_\_\_ Month and Year \_\_\_\_\_

Address \_\_\_\_\_ Number of Visits this Month \_\_\_\_\_

EXERCISES  List specific exercises for individual joints: number of repetitions and frequency; method in which passive motion is carried out; etc.	Remarks:			
	Assisted Patient	Tested or Observed Performance	Instructed Patient Verbal/Demons.	Instructed Family Member or Other
1.				
2.				
3.				
4.				
5.				
6.				
7.				

Nurse or Physical Therapist \_\_\_\_\_

V.N.A. Monthly Activity Record - Prescribed Treatment

Patient's Name \_\_\_\_\_ Month and Year \_\_\_\_\_

PRESCRIBED TREATMENT Medications; Dressings; Treatments; Orthopedic Equipment (List as Prescribed)	Remarks			
	Administered	Reviewed Procedure	Instructed Patient	Instructed Family Member or Other
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				

Nurse or Physical Therapist \_\_\_\_\_

Effects of Continued Care

V.N.A. Monthly Activity Record - ADL

Patient's Name \_\_\_\_\_ Month and Year \_\_\_\_\_

ACTIVITIES OF DAILY LIVING	Remarks:			
	Assisted Patient or Gave Care	Tested or Observed	Instructed Patient	Instructed Family Member or Other
Bathing				
Dressing				
Going to Toilet and Toilet Training				
Transfer				
Feeding				
Walking				
Stair Climbing				
Wheelchair Management				
Other (Specify)				
Other				
Other				

Nurse or Physical Therapist \_\_\_\_\_

V.N.A. Monthly Activity Record - Planning and Coordination

Month of Follow \_\_\_\_\_

Date Due \_\_\_\_\_

Patient's Name \_\_\_\_\_ Month and Year \_\_\_\_\_

HEALTH PROMOTION	Remarks:					
	Listened with Appropriate Response		Identified Problem		Interpreted and/or Instructed	
	Patient	Family	Patient	Family	Patient	Family
Nutrition						
Accident Prevention						
Medical Supervision						
Personal Hygiene						
Home Management						
Recreation						
Other (Specify)						

PLANNING AND COORDINATION  (Indicate individual or group with whom you are working.)	Remarks:			
	Identified Problems	Transmitted Reports	Developed Plan	Made Referral
Patient and Family	<del> </del>	<del> </del>		<del> </del>
Physician				
Other (Specify individual or group)				
1.				
2.				
3.				
4.				
5.				

Nurse \_\_\_\_\_

Effects of Continued Care

V.N.A. Monthly Activity Record - Psychological Therapy

Patient's Name \_\_\_\_\_ Month and Year \_\_\_\_\_

PSYCHOLOGICAL THERAPY	Remarks:					
	Listened with Appropriate Response		Interpreted		Proposed Action	
	Patient	Family	Patient	Family	Patient	Family
Reaction to Illness						
Disease Process and Prognosis						
Social and Economic Problems						
Limitations Imposed by Illness:						
Physical						
Economical						
Social						
Feelings about the Treatment Plan						
Interpersonal Relations with the Family						
Other (Specify)						
Other						
Other						

Nurse \_\_\_\_\_

## SUPPLEMENTARY DEFINITIONS

The following information supplements information about measures described in Chapter 5. For measures that are not described adequately in published literature, definitions are expanded to aid the research observer in completing the preceding forms.

*Study Form A-2.*

The occupation of a woman's husband is ordinarily the occupation factor used in defining socioeconomic class by Hollingshead's Two Factor Index of Social Position; however, it is not appropriate to use the husband's occupation for certain aged, long-retired, and long-widowed people. After consulting Dr. Hollingshead, the following modified definitions have been accepted for this study. Unless otherwise defined herein, the occupation used in calculating the Index of Social Position is that of the male head of the household, even if retired. Women are, thus, classified according to their husband's highest occupational level as in the case of housewives, widows who have never worked, divorcees who have never worked, and women who have been widowed for less than ten years. If unmarried, widowed for more than ten years and working, widowed for more than ten years and retired, divorced and working, or divorced and retired, the *woman's* usual occupation is used in calculating the Index position.

*Study Form A-4.*

The *Index of Independence in Socioeconomic Functioning* was developed to measure socioeconomic function of the aged (The Staff of The Benjamin Rose Hospital: Multidisciplinary Studies of Illness in Aged Persons. A New Classification of Socioeconomic Functioning of the Aged. *J. Chron. Dis.* 13: 453, 1961). A modified form, namely, the *Index of Economic Dependence*, is used in the present study and incorporates indicators of resources and productivity as defined below.

The observer records the economic status of patients as it existed during the 2-week period which preceded the due date of the evaluation.

At the time of the initial research evaluation, the period of evaluation is defined as the 2-week period which preceded the current period of continuous hospitalization. As a guide to the interviewer who is responsible for completing Study Form A-4, additional details of definition are presented here concerning the terms *gainful employment*, *home ownership*, and *agency support*.

Patients are considered *gainfully employed* if they derive income from an activity which they perform regularly at least one hour each week, including even such activities as baby sitting or active involvement in managing a boarding home.

In general, *home ownership* is identifiable precisely; however, certain clarifications of definition assure comparable recording for use in the Index. Since the concern here is with functional residence, a patient who lives in a residence which he does not own is classed as "not" the home owner though he may be the legally designated owner of some other dwelling, while a patient who lives in a residence that he or his spouse owns is considered to be the home owner whether he or someone else pays the property taxes. A patient who is co-owner of his place of residence is, also, classed as a home owner. Trailer ownership is not defined as home ownership unless the patient or his spouse own the land or pay taxes on the land on which the trailer stands.

In order to determine the presence or absence of *agency support*, the observer reviews the sources of funds used for the patient's food, clothing, residence tax or rent, medicines, and doctor's fees. Though all of the information gathered in this question is not needed in order to determine the presence or absence of agency support, the detailed review assures the best possible validity and reliability of the measure. An agency is defined as any social service or charitable agency, local, county, state, or national, private or public, which assigns funds to the patient or his spouse for the aforementioned needs. Social Security, veterans' pensions,

unemployment compensation, family assistance, rental from properties, and retirement plans such as industrial and teachers' retirement plans are not classified as sources of agency support in the *Index of Economic Dependence*. For the purposes of this measure, food coupons or certificates are defined as funds, while free services or equipment are not so defined. Payment by another of a patient's monetary obligations are considered as use of "funds" though the money may not be given directly to the patient.

Based on the above definitions, the following four grades are included in the *Index of Economic Dependence* in order of increasing economic dependence. *Grade 1* includes people who own their residence, are employed, and do not receive agency support. *Grade 2* includes people who are either unemployed or do not own their residence (not both), and do not receive agency support. *Grade 3* includes people who either receive agency support or do not own their residence (not both), and are unemployed. *Grade 4* includes people who are unemployed, do not own their residence, and receive agency support.

#### *Study Form A-5.*

Evaluations of bathing, dressing, going to toilet, transferring, continence, and feeding comprise the measures of self-function in individual activities of daily living. Functional status in these activities have been summarized in a standardized measure, the *Index of ADL*, which reflects the adequacy of organized neurological and locomotor response and which serves as a graded measure of such biological and psychosocial function (Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A. and Jaffe, M.W.: *Studies of Illness in the Aged, The Index of ADL: a Standardized Measure of Biological and Psychosocial Function.* J.A.M.A. 185:914, 1963).

By means of a series of questions and observations, the observer forms a mental picture of the patient's ADL status as it existed during the 2-week period which preceded the due date of the evaluation. The observer determines whether another person assisted the patient or whether the patient functioned alone, defining assistance

as *active personal assistance, directive assistance, or supervision*. The actual existence of such assistance is considered in the evaluation, *not* the potential or ability of the patient. Thus, for example, overprotective assistance is defined as assistance though the observer considers the patient as more able, and refusal to perform a function is defined as nonfunctioning though the patient is deemed able. The observer uses the following definitions in completing Study Form A-5 and, in general, records the most dependent degree of function which was performed during the 2-week period.

*Bathing* is the overall complex behavior of getting water and cleansing the whole body. A patient receives "no assistance" (first of the three classes of bathing on Study Form A-5) if no other person is involved in any part of the process of taking a sponge, shower, or tub bath to wash the whole body. Such a patient goes to the sink by himself if he sponge-bathes at the sink, gets in and out of a tub by himself if he tub-bathes, and is not supervised in the shower if showering is the means of bathing. A patient receives "assistance in bathing only one part of the body" if he functions by himself as defined above, except that he is assisted in washing only one part of the body, as his back alone or one leg alone. The class "assistance in bathing more than one part of the body" includes the individual who is assisted in washing more than one part of the body or who does not bathe. This last, most dependent category, includes also the following: the patient to whom water is brought even though he washes himself; the patient who is taken to the place of bathing though he washes himself; the person who is helped in or out of a tub as regularly as once a week; the patient who is regularly supervised for reasons of safety though he washes himself; and the patient who can't reach his feet to wash them.

*Dressing* is the overall complex behavior of getting clothes from closets and drawers and then getting dressed. A patient gets "completely dressed without assistance" (first of the three classes of dressing on Study Form A-5) if no other person is involved in getting clothes from closets and drawers nor in putting on the clothes, including brace, if worn, and including

outer garments and footwear. Fasteners must also be managed without assistance. Footwear include such items as socks and slippers or shoes. The intermediate category of dressing on Study Form A-5 includes those who get their own clothes and dress independently as defined above "except for assistance in tying shoes." A patient is placed in the third and most dependent category if he receives "assistance in getting clothes or in getting dressed" or remains "partly or completely undressed."

*Going to toilet* is the act of going to the room termed the "toilet room" for bowel and bladder function, transferring on and off the toilet, cleaning after elimination, and arranging clothes. The patient who functions wholly by himself, including getting to the room, is classed as functioning "without assistance" (first of the three classes of toileting on Study Form A-5). It should be noted that an individual in this class may or may not be using an object for support such as a cane, walker, or wheelchair; and he may be using a bedpan or commode at night, in which case he empties it himself to be considered in the "without assistance" category. If another person assists in any part of the function, the toileting status is recorded as "receives assistance" (intermediate toileting category on Study Form A-5). Toileting status is also recorded as "receives assistance" for an individual who uses the toilet room at certain times, and at other times uses a daytime bedpan or commode. The third category, namely, "doesn't go to room termed toilet", is self-explanatory. Note that toileting is *not* concerned with continence. A patient is occasionally incontinent, but manages himself completely independently insofar as toileting is concerned. Toileting function, for this patient, is recorded as "without assistance."

*Transfer* is the process of moving in and out of bed and in and out of a chair. If no other person is involved in the transfer, the patient is considered to function "without assistance" (first of three classes of transfer on Study Form A-5). Such a patient may be using an object for support, e.g., cane, walker, or bedpost. The intermediate category, namely, "with assistance", applies if another person is involved in the process. Patients in the third category are

bedridden and do not leave the bed at all. In evaluating transfer status, the observer may be told that the patient is not allowed to transfer unless supervised for reasons of safety. The observer then tries to observe whether such supervision is a reality. The observer may occasionally find, for example, that a daughter claims she supervises her mother whenever her mother moves from one place to another, while observation reveals that the mother moves about entirely on her own, and the daughter actually means that she is always within hearing distance.

*Continence* refers to the physiologic process of elimination from bladder and bowel, where incontinence is the involuntary loss of urine and/or feces. The function is thought of as the primitive function of control and does not include any consideration of hygiene, toileting, or constipation. The patient is classed as "controls urination and bowel movement completely by self" (first of three continence categories on Study Form A-5) if no other person assists. Such a patient can exert some degree of control on the process himself by medication or by self-administered enema (or, in the case of patient with a colostomy, may manage this by himself). A slight amount of wetness or slight soiling of underclothes is occasionally noted by others and is not perceived as incontinence by the patient, in which case status is recorded as "controls urination and bowel movement." The patient who does not get to the bathroom or commode on time or who is incontinent at least once during the 2-week period of the evaluation is considered as "has occasional accidents", the intermediate category. Patients in the third category are incontinent or controlled by the supervision, direction, or intervention of another person. Presence of a catheter or planned supervised scheduling for bowel control are included in the incontinent category.

*Feeding* concerns the process of getting food from a plate or its equivalent into the mouth. It is considered in a primitive sense and without concern for social niceties. A patient feeds himself "without assistance" (first of three classes of feeding on Study Form A-5) when this primitive process of ingestion is accomplished without the aid of another person. The

intermediate category on Study Form A-5 applies to the individual who feeds himself, but receives assistance in cutting meat or buttering bread. The third category on Study Form A-5, "receives assistance", applies to the individual who is assisted in this feeding process or who is fed partly or completely parenterally.

In addition to the Index of Independence in Activities of Daily Living, separate measures of walking and house-confinement are recorded on Study Form A-5. Five categories of walking are identified as follows: (1) "walks on level without assistance"; (2) "walks without assistance but uses single, straight cane"; (3) "walks without assistance but uses 2 points for mechanical support, such as crutches, a walker, or 2 canes (or wears a brace)"; (4) "walks with assistance"; (5) "uses wheelchair only"; and (6) "neither walking nor using wheelchair" (Katz, S., Ford, A.B., Heiple, K.C. and Newill, V.A.: *Studies of Illness in the Aged. Recovery after Fracture of the Hip.* J. Gerontol. 19:285, 1964). These six categories are defined as mutually exclusive; thus category "4" applies to patients who walk with assistance whether they do or do not use mechanical aids, and category "5" includes only those who use a wheelchair and do not walk at all. As indicated before for other functions, the observer records the most dependent level of walking which was performed during the 2-week period of evaluation. A patient who walks about unassisted in the home is, thus, designated as "walks with assistance" if she is assisted or supervised outdoors. The observer is occasionally told that the patient is not permitted to walk unless supervised for reasons of safety. In such cases, direct observation of walking status is needed to determine whether supervision is actually present or whether supervision is claimed merely because assistance is within hearing distance.

As a measure of patient confinement, observers record on Study Form A-5 the degree of house-confinement in the following terms: (1) "has been outside of residence on 3 or more days during past 2 weeks"; (2) "has been outside of residence on only 1 or 2 days during past 2 weeks"; and (3) "has not been outside of residence in past 2 weeks." At the time of the initial

research evaluation, the period of evaluation is defined as the 2-week period which preceded the current period of continuous hospitalization. The trip home, immediately after intake into the study, is excluded from this measurement. The term "outside" means outside of the enclosed, personal living quarters of the patient. "Outside" may be the backyard, terrace, patio, or porch of the dwelling. It may also be another apartment or the hall in the building in which the patient has his apartment suite.

#### *Study Form A-10.*

The test of range of movement and strength was developed to meet the need for an objective, easily applied, and standardized measure which could be administered to elderly people. The test was developed as a simplified form of previously described, more extended tests (Daniels, L., Williams, M. and Worthingham, C.: *Muscle Testing Techniques of Manual Examination*, published by W. B. Saunders Company, 2nd Edition, 1961). (Committee on Medical Rating of Physical Impairment: *A Guide to the Evaluation of Permanent Impairment of the Extremities and Back.* J.A.M.A., Special Edition, Feb. 15, 1958). Though easily learned by an examining physician, successful and reliable use requires careful adherence to the following definitions and procedures.

The *range of a given movement* is measured in degrees and is the angle formed in moving the limb from a stationary or zero starting point to the position of completion. In the starting position, the patient sits erect in a chair with arms. The chair's seat is 16 to 18 inches from the floor, and the supports for the arms of the chair are recessed at least 4 to 6 inches from the front corners of the seat. The patient's head is positioned high, maintaining the normal curve of the cervical spine; and the patient sits as erectly as possible with his back against the back of the chair. The scapulae are in the normally-adducted rest position. The upper arms parallel the sides of the trunk, while the forearms are in a neutral position, slightly flexed at the elbow and in a position between pronation and supination. The hips are flexed with the gluteal region positioned to the rear of the seat against the back of the

chair. The knees are flexed, and the feet are flat on the floor with toes pointed directly ahead.

The range of movement for each of the sixteen maneuvers of the test is defined in Figure XIII-2 and is expressed as the minimum range which must be completed in order to consider that the movement is performed. If the minimum acceptable range is completed in the proper positions and directions, the block for the appropriate maneuver is checked in the column labeled "Does" on Study Form A-10. If the patient does not complete the minimum acceptable range, the block is checked in the column labeled "Does Not". In some cases, the use of a goniometer may be necessary to measure the angle of movement. For some patients, also, demonstration of maneuvers is required.

*Fixation* is the process by which the appropriate body position is maintained to permit the muscles involved in a given maneuver to be tested without the use of other muscles. Adequate fixation ensures that only the muscles of concern are responsible for the movement and that substitution of other muscles does not occur. In Figure XIII-2 the region of fixation or stabilization is defined for each maneuver. Some patients cannot maintain the appropriate body position, and the examiner may have to isolate the test maneuver by manual stabilization. The examiner is trained to avoid substitute actions and is on the alert for even subtle substitutions. For subjects with adequate strength, certain maneuvers can be tested in the left and right limbs spontaneously; and substitution is less likely to occur.

*Resistance* is the force exerted by the examiner in opposition to the patient's muscle power. The patient's power to oppose resistance is an indicator of patient strength; and, in the present test, the patient is classed on Study Form A-10 as performing "Against resistance" when he exerts even slight strength in opposition to the examiner's resistance. The examiner's force is exerted in a direction opposite to force vector of the movement being tested, and the points of application are defined in Figure XIII-2. Resistance is applied when the patient

has completed the minimum acceptable range of movement.

In this test, the patient is asked to perform a series of six maneuvers with each lower limb and 10 maneuvers with each upper limb. All maneuvers are tested both with and without resistance. Maneuvers are tested using defined positions for evaluating movement, defined points for applying resistance, defined avoidance of substitute maneuvers, and standardized definitions of range of movement in degrees. Test maneuvers of the lower limb include movements of the hip, knee, and ankle. Patients are instructed as follows: (1) kick foot into air; (2) bring knee toward chest; (3) bring leg out to side, (4) return leg to center; (5) move foot from side to side; and (6) bend foot up and down. In testing the function of the upper limb, patients are instructed to move the shoulder, elbow, wrist, hand, and fingers as follows: (1) raise arm forward high above head; (2) put hand on back of head; (3) swing arm toward and away from midline at shoulder level; (4) bring hand to front of shoulder; (5) with elbow at shoulder level, straighten out arm; (6) wave hand from side to side; (7) grasp small object with fingers; (8) extend fingers, (9) touch tip of thumb with little finger; and (10) after touching fingertip, extend thumb. Each movement is demonstrated by the examiner when necessary.

Observations are recorded on Study Form A-10 according to the procedures and definitions described herein. For the purposes of the analyses in this study, function is recorded as "Does not" whenever the degree of function defined in Figure XIII-2 is not achieved. The reason for non-achievement is not considered; thus, function is recorded as "Does not" for the patient who does not cooperate, as well as for the patient with an amputation.

Four grades of function are recognized for each lower limb; namely, grades L1, L2, L3, and L4. Nonfunction in at least 5 of the 6 maneuvers of a lower limb constitutes the lowest grade, L4, for that limb. Nonfunction in 2 to 4 of the 6 maneuvers of a lower limb is graded as L3. A grade of L2 is assigned to a lower limb which is functional in at least 5 of the 6 test maneuvers and which functions against resistance in no

Effects of Continued Care

Range of Movement	Region To Be Stabilized	Point of Application of Resistance
<u>Kick foot into air</u> - knee extended to at least 170° with foot off floor	Thigh proximal to knee	Dorsal area of ankle
<u>Bring knee toward chest</u> - thigh proximal to knee joint lifted at least 10° off seat of chair	Stabilized by trunk	Thigh proximal to knee joint
<u>Bring straight leg out to side</u> - leg brought at least 15° away from midline with knee as straight as possible - heel may be dragged on floor and patient may slouch	Pelvis	Lateral malleolus
<u>Return leg to center</u> - abducted leg moved at least 15° toward midline with knee as straight as possible - heel may be dragged on floor and patient may slouch	Pelvis	Medial malleolus
<u>Move foot from side to side</u> - dorsiflexed foot moved at least 5° from side to side - examiner may support suspended leg off floor	Distal tibia	Metatarsophalangeal joint of great toe for inversion and MP joint of small toe for eversion
<u>Bend foot up and down</u> - foot moved upward and downward at least 10° from neutral position	Distal tibia	Dorsum of metatarsals for dorsiflexion and plantar area of metatarsals for plantar flexion
<u>Raise straight arm forward high above head</u> - hand and arm raised forward from neutral position to a position at least above shoulder level with elbow extended as much as possible and with forearm partly or wholly supinated	Top of shoulder girdle	Flexor surface of forearm adjacent to wrist
<u>Put hand on back of head</u> - arm raised sideways at least 75° with elbow flexed and then hand raised at least 45° toward occiput - hand need not touch back of head	Top of shoulder girdle	Dorsal surface of forearm adjacent to wrist
<u>Swing straight arm toward and away from midline at shoulder level</u> - extended arm moved at least 75° away from and toward midline at shoulder level with hand partly or wholly supinated - acceptable if extended arm is partly raised from body though it may not be at shoulder level	Shoulder girdle	Dorsal and flexor surfaces, respectively, of forearm adjacent to wrist
<u>Bring hand to front of shoulder</u> - elbow flexed and forearm moved at least 90° toward shoulder from position in which elbow is extended and forearm is wholly or partly supinated - examiner may support upper arm at shoulder level if necessary	Upper arm adjacent to elbow	Flexor surface of forearm adjacent to wrist

Figure XIII-2. Definitions for Test Range of Movement and Strength

<u>With elbow at shoulder level, straighten out arm</u> - forearm extended to within at least 10° of full extension from position in which elbow is flexed - examiner may support upper arm at shoulder level if necessary	Upper arm adjacent to elbow	Dorsal surface of forearm adjacent to wrist
<u>Wave hand from side to side</u> - wrist flexed ventrally at least 25° and dorsally at least 15° with forearm midway between pronation and supination - forearm may be supported if necessary	Forearm adjacent to wrist	Palm and dorsum of hand, respectively, at metacarpophalangeal joints
<u>Grasp small object with fingers</u> - object with circumference of pen grasped and supported	Proximal hand	Each finger pulled lightly
<u>Extend fingers</u> - all fingers extended to approximately 180°	Proximal hand	Dorsal distal tip of each finger
<u>Touch tip of thumb with tip of little finger</u> - pads of tips of little finger and thumb brought into contact	Proximal hand	Palm at distal end of first and fifth metacarpals
<u>After touching tip of little finger, extend thumb</u> - thumb extended fully	Proximal hand	Dorsum of distal phalanx

Figure XIII-2. Continued

more than 1 of the 3 knee and ankle maneuvers. A grade of L1 is assigned to a lower limb which is functional in at least 5 of the 6 test maneuvers and which functions against resistance in at least 2 of the 3 knee and ankle maneuvers.

Three grades are recognized for each upper limb, namely, U1, U2, and U3. Nonfunction in at least 9 of the 10 maneuvers of an upper limb is graded as U3. A grade of U1 is assigned to an upper limb, if at least 2 of the 3 shoulder maneuvers are functional and, at the same time, if function is present against resistance in at least 6 of the 7 elbow, wrist, fingers, and thumb maneuvers. A grade of U2 is assigned to an upper limb which functions better than a grade of U3 and worse than a grade of U1.

#### *Study Form A-20*

The *Highland View Hospital Scale of Psychosocial Adjustment* uses a Q-sort technique to rate behavior of elderly patients with emphasis on adjustment to disability and to rehabilitation. (Shontz, F. C. and Fink, S. L.: *A Method for Evaluating Psychosocial Adjustment of the*

*Chronically Ill*. *Am. J. Physical Med.* 40: 63-69, 1961). For the measure, each of a series of thirty-six descriptive statements about behavior is printed on a single card. The rater, on the basis of his best knowledge of the patient, sorts the set of cards into three piles, placing those statements which best describe the patient to the right, those which are least like the patient to the left, and the remaining cards in the middle. A further breakdown of the cards is performed until a final distribution is attained in which seven piles exist with 2, 4, 6, 12, 6, 4, and 2 cards in the respective piles from left to right. The coded identities of the items are recorded in the corresponding seven columns of Study Form Number 20. Items which reflect appropriate adjustment are weighted by factors of 0 to 6 as specified for the respective columns on Study Form Number 20, and then summed. Items which reflect poor adjustment are weighted similarly and then summed. The difference between these sums is the total adjustment score. Subscores can be calculated for subtest areas of motivation, social adjustment, and personal adjustment.

Effects of Continued Care

Items concerned with motivation are specified as:

Reasonably cooperative in carrying out medical procedures,

Comprehends physical condition realistically,

Moderately active, considering his disability,

Appraises his capacities accurately,

Thwarts purposes of medical care,

Misinterprets reality of his illness,

Avoids any form of exertion (by desire rather than necessity),

Thinks he can do anything,

Overly meticulous in obedience to medical requirements,

Preoccupied with the facts of his illness,

Constantly busy with unproductive activities,

Devaluates his own abilities.

The first four items in the above list are considered to be descriptive of appropriate adjustment.

Items concerned with social adjustment are specified as:

Family treats him as an equal,

Is accepted by family for what he really is,

Maintains mature social relationships,

Expresses appropriate feelings for family,

Other members of family make all decisions for him,

Over-protected at home,

Isolates self from others,

Always fighting with family members,

"Rules the roost" at home,

Clings to others for help,

Family resents his presence,

Overly devoted to his family.

The first four items in the above list are considered to be descriptive of appropriate adjustment.

Items concerned with personal adjustment are specified as:

Lives as well as possible within the physical limits of disability,

Emotional reactions are appropriate,

Adaptable in his thinking,

Accepts necessary misfortunes,

Constantly tense,

Apathetic,

Has set ideas he won't give up,

Blames others whenever something goes wrong,

Denies disability,

Intellectually chaotic and unpredictable,

"Uses" disability for selfish ends,

Always sees himself at fault.

The first four items in the above list are considered to be descriptive of appropriate adjustment.

## CHAPTER XIV. INTAKE AND OUTCOME VARIABLES

Patients in the study were categorized into INTAKE CLASSES at the beginning of the study and into OUTCOME CLASSES during the course of the study. This served the purposes of the analyses described in Chapter 12. On the following pages, short definitions and explanatory remarks are presented for 71 intake classes and 28 outcome classes. The lists of classes were useful in programming for the study, and they are reproduced here as aids to the perception of methods, data, and results of the study. For additional information about definitions, the reader should consult the Index of the book.

After every definition in the column labelled "Class Definition", two numbers are set off by parentheses. The first number is the number of people in the total study group of 300 who were known to be *in* the defined class. The second number is the number of people who were known to be *not in* the class. The difference between the sum of these two numbers and the total number of patients (300) is the number in which the class status is not applicable or unknown. As an example, we consider "intake class #2: patients with ADL rating of F or G (92, 208)". In this example, 92 patients had ADL ratings of F or G; and 208 patients had

other ADL ratings. Since the sum of 92 and 208 accounts for all 300 patients, we deduce that there were no patients of unknown ADL status at intake. As another example, we consider "intake class #61: patients who have daily contact with no one (59,236)". In this example, 59 patients were known to have daily contact with no one; and 236 patients were known to have daily contact with others. Since the sum of 59 and 236 accounts for 295 patients, we deduce that the presence or absence of daily contact was unknown for five patients. For each outcome class, reasons for excluding patients from the class are explained in the column labelled "Remarks" and help to clarify the meaning of the numbers within the parentheses. As an example, we consider "outcome class #3: patients who deteriorated in ADL rating during the study (36, 176)". In this example, 36 patients deteriorated in ADL rating during the study, and 176 maintained or improved their ADL ratings. Patients who died were excluded from analysis, and outcome class #2 indicates that 87 patients died during the study. Since the sum of 36, 176, and 87 accounts for 299 patients, we deduce that outcome in terms of a change in ADL rating was unknown for one patient.

### INTAKE VARIABLES

<u>Intake</u> <u>Class No.</u>	<u>Class Defini:</u>
#1	All patients, inclusive (300, 0)
#2	Patients with ADL rating of F or G (92, 208)

Effects of Continued Care

<u>Intake Class No.</u>	<u>Class definition</u>
#3	Patients not in intake class #2; and with at least one of cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (81, 219)
#4	Patients in neither intake class #2 nor #3 (127, 173)
#5	Patients not in intake class #2; and with at least one of cancer within 5 years, abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, or on digitalis (111, 189)
#6	Patients in neither intake class #2 nor #5 (97, 203)
#7	Patients not in intake class #2; and with at least one of cancer within 5 years, abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, or diastolic blood pressure of 90 or greater (104, 195)
#8	Patients in neither intake class #2 nor #7 (103, 196)
#9	Patients not in intake class #2; and with at least one of cancer within 5 years, abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, on digitalis, or diastolic blood pressure of 90 or greater (130, 169)
#10	Patients in neither intake class #2 nor #9 (77, 222)
#11	Patients not in intake class #2; and with at least one of cancer within 5 years, abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, on digitalis, diastolic blood pressure of 90 or greater, or proteinuria of 2-plus or greater (133, 166)
#12	Patients in neither intake class #2 nor #11 (74, 225)
#13	Patients with ADL rating of A, B, C, or D (78, 222)
#14	Patients with ADL rating of E, F, or G (222, 78)
#15	Patients with ADL rating of A, B, C, D, or E (208, 92)
#16	Patients in intake class #13; and with at least one of Raven test score of 12 or less, or orientation and mental control test score of 13 or less (8, 286)

<u>Intake Class No.</u>	<u>Class definition</u>
#17	Patients in intake class #13; and with neither Raven test score of 12 or less, nor orientation and mental control test score of 13 or less (64, 230)
#18	Patients in intake class #14; and with at least one of Raven test score of 12 or less, or orientation and mental control test score of 13 or less (67, 213)
#19	Patients in intake class #14; and with neither Raven test score of 12 or less, nor orientation and mental control test score of 13 or less (135, 145)
#20	Patients in intake class #15; and with at least one of Raven test score of 12 or less, or orientation and mental control test score of 13 or less (31, 258)
#21	Patients in intake class #15; and with neither Raven test score of 12 or less, nor orientation and mental control test score of 13 or less (166, 123)
#22	Patients in intake class #15; and with at least one of Raven test score of 12 or less, or orientation and mental control test score of 13 or less (44, 241)
#23	Patients in intake class #2; and with neither Raven test score of 12 or less, nor orientation and mental control test score of 13 or less (33, 252)
#24	Patients in intake class #2 with no cancer within 5 years; and with at least one of abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, on digitalis, diastolic blood pressure of 90 or greater, or proteinuria of 2-plus or greater (59, 241)
#25	Patients in intake class #15 with no cancer within 5 years; and with at least one of abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, on digitalis, diastolic blood pressure of 90 or greater, or proteinuria of 2-plus or greater (115, 184)
#26	Patients with at least one of intake class #2, Raven test score of 12 or less, or orientation and mental control test score of 13 or less; and with no cancer within 5 years; and with at least one of abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, on digitalis, diastolic blood pressure of 90 or greater, or proteinuria of 2-plus or greater (77, 218)
#27	Patients in intake class #21 with no cancer within 5 years; and with at least one of abnormal Q-wave on electrocardiogram, blood urea nitrogen level of 30 mg. per 100 ml. or greater, on digitalis, diastolic blood pressure of 90 or greater, or proteinuria of 2-plus or greater (92, 202)

Effects of Continued Care

<u>Intake Class No.</u>	<u>Class definition</u>
#28	Patients with principal diagnosis of stroke; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (60, 238)
#29	Patients with principal diagnosis of stroke; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (15, 283)
#30	Patients with principal diagnosis of stroke or chronic brain syndrome; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (76, 221)
#31	Patients with principal diagnosis of stroke or chronic brain syndrome; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (18, 279)
#32	Patients with principal diagnosis of stroke, chronic brain syndrome, or brain diseases other than stroke and other than chronic brain syndrome; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (90, 207)
#33	Patients with principal diagnosis of stroke, chronic brain syndrome, or brain diseases other than stroke and other than chronic brain syndrome; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (21, 276)
#34	Patients with principal diagnosis of fracture of femur; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (34, 264)
#35	Patients with principal diagnosis of fracture of femur; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (23, 275)
#36	Patients with principal diagnosis of fracture of femur or fracture of lower limb other than fracture of femur; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (41, 257)

<u>Intake Class No.</u>	<u>Class definition</u>
#37	Patients with principal diagnosis of fracture of femur or fracture of lower limb other than fracture of femur; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (28, 270)
#38	Patients with principal diagnosis of fracture of femur, fracture of lower limb other than fracture of femur, or muscular or skeletal conditions other than fracture of femur and other than other fractures of lower limb; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (57, 239)
#39	Patients with principal diagnosis of fracture of femur, fracture of lower limb other than fracture of femur, or muscular or skeletal conditions other than fracture of femur and other than other fractures of lower limb; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (53, 243)
#40	Patients with principal diagnosis of arthritis (31, 269)
#41	Patients with principal diagnosis of cardiovascular-renal diseases; and with at least one of intake class #2, Raven test score of 12 or less, orientation and mental control test score of 13 or less, cancer within 5 years, abnormal Q-wave on electrocardiogram, or blood urea nitrogen level of 30 mg. per 100 ml. or greater (77, 221)
#42	Patients with principal diagnosis of cardiovascular-renal diseases; and in intake class #21; and with neither cancer within 5 years, abnormal Q-wave on electrocardiogram, nor blood urea nitrogen level of 30 mg. per 100 ml. or greater (24, 274)
#43	Men (99, 201)
#44	Women (201, 99)
#45	Patients younger than 65 years (75, 225)
#46	Patients 65 through 74 years old (99, 201)
#47	Patients 75 years old or older (126, 174)
#48	Patients with Hollingshead Index Social Class of either I, II, or III (121, 179)

Effects of Continued Care

<u>Intake</u> <u>Class No.</u>	<u>Class definition</u>
#49	Patients with Hollingshead Index Social Class of either IV or V (179, 121)
#50	Patients who own their residence, are employed, and do not receive agency support; or Patients who are either unemployed or do not own their residence (not both), and do not receive agency support (133, 167)
#51	Patients who either receive agency support or do not own their residence (not both), and are unemployed; or Patients who are unemployed, do not own their residence, and receive agency support (167, 133)
#52	Patients who terminated employment or homemaking within the 30 days prior to admission to Abington House (112, 188)
#53	Patients who terminated employment or homemaking between 30 days and 2 years prior to admission to Abington House (98, 202)
#54	Patients in neither intake class #52 nor #53 (90, 210)
#55	Patients who are married and live with spouse (111, 189)
#56	Patients who do not live with spouse and do not live alone (103, 197)
#57	Patients who live alone (85, 215)
#58	Patients who live with spouse or child (162, 138)
#59	Patients who have daily contact with two or three categories of persons (spouse, other relatives, friends) (71, 224)
#60	Patients who have daily contact with one category of persons (spouse, other relatives, or friends) (165, 130)
#61	Patients who have daily contact with no one (59, 236)
#62	Patients who talk to more than 5 people daily (111, 170)
#63	Patients with any regular organized social activities (church, clubs, etc.) (134, 164)

<u>Intake Class No.</u>	<u>Class definition</u>
#64	Patients who were gainfully employed during the two weeks prior to hospitalization in Abington House (45, 255)
#65	Patients in intake class #59, and in at least one of intake class #62, #63, or #64 (50, 245)
#66	Patients in intake class #60, and in at least one of intake class #62, #63, or #64 (105, 191)
#67	Patients in intake class #61, and in at most one of intake class #63 or #64 (42, 252)
#68	Patients in intake class #53, or who lost spouse in the 2-year period prior to study (104, 196)
#69	Patients not in intake class #68 (196, 104)
#70	Patients who talk to fewer persons daily than they did at age 45 (222, 71)
#71	Patients not in intake class #70 (71, 222)

### OUTCOME VARIABLES

<u>Outcome Class No.</u>	<u>Class Definition</u>	<u>Remarks</u>
#1	All patients, inclusive (300, 0)	
#2	Patients who died during the study (87, 213)	For interval analyses, this class included all patients, cumulatively, who died at any time between intake and the end of each quarterly interval.
#3	Patients who deteriorated in ADL rating during the study (36, 176)	Deterioration was any change from left to right in the following graded Index of ADL ratings as defined in Chapter 5: <i>A, B, C, D, E, F, G</i> . If the rating was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between ADL ratings at intake and ADL ratings at the end of each quarterly interval.

Effects of Continued Care

<u>Outcome Class No.</u>	<u>Class Definition</u>	<u>Remarks</u>
#4	Patients who deteriorated in walking during the study (30, 182)	Deterioration was any change from left to right in the following graded walking scale as defined in Chapter 5: walking by self or with no more assistance than a cane, walking with mechanical assistance, walking with personal assistance (with or without mechanical assistance), not walking at all. If the walking status was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between walking status at intake and walking status at the end of each quarterly interval.
#5	Patients who became more house-confined during the study (54, 157)	Increased house-confinement was any change from left to right in the following graded classification as defined in Chapter 5: out of residence 3 or more times during the 2-week reference period, out 1 or 2 times, out at no time. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between house-confinement at intake and house-confinement at the end of each quarterly interval.
#6	Patients who suffered a fracture during the study (35, 193)	Patients who had fractures during the study, including those who later died, were counted as being in this class. Those whose fracture status was unknown or who died without having suffered a fracture were excluded from analysis. For interval analyses, this class included all patients, cumulatively, who had suffered fracture at any time between intake and the end of each quarterly interval.
#7	Patients who deteriorated in upper limb function during the study (27, 185)	Deterioration was any change to a decreased level of function as measured by the 3 grades of the test of upper limb range of movement and strength defined in Chapter 5. If the grade was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. Interval analyses were not possible, since range of movement and strength were tested only at intake and at terminal.
#8	Patients who deteriorated in lower limb function during the study (26, 185)	Deterioration was any change to a decreased level of function as measured by the 4 grades of the test of lower limb range of movement and strength defined in Chapter 5. If the grade was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. Interval analyses were not possible, since range of movement and strength were tested only at intake and at terminal.

<u>Outcome Class No.</u>	<u>Class Definition</u>	<u>Remarks</u>
#9	Patients who deteriorated in the function of any limb during the study (43, 169)	Deterioration was any change to a decreased level of function in any upper or lower limb as measured by the test of range of movement and strength defined in Chapter 5. If the level of function was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. Interval analyses were not possible, since range of movement and strength were tested only at intake and at terminal.
#10	Patients who deteriorated in observation and clear thinking during the study (85, 95)	Deterioration was any change to a lower score according to the Raven test described in Chapter 5. If the score was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. Interval analyses were not possible, since the Raven Test was given only at intake and terminal.
#11	Patients who deteriorated in orientation and mental control during the study (68, 128)	Deterioration was any change to a lower score according to the test of orientation and mental control described in Chapter 5. If the score was the same or better at terminal than at intake, there was no deterioration. Excluded from analysis were those who died and those for whom information was insufficient. Interval analyses were not possible, since the test of orientation and mental control was given only at intake and at terminal.
#12	Patients who received financial assistance from a charitable agency during the study, but not at intake (13, 198)	Patients who received charitable assistance during the study, including those who later died, were counted as being in this class. Those whose assistance status was unknown or who died without receiving charitable assistance were excluded from analysis. For interval analyses, this class included all patients, cumulatively, who had received financial assistance from a charitable agency through the end of each quarterly interval and who had not received such assistance at intake as defined in Chapter 5.
#13	Patients who had been gainfully employed at intake and were not employed at terminal (19, 193)	Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between employment status at intake (defined in Chapter 5) and employment status at the end of each quarterly interval.
#14	Patients who decreased their social activities during the study (69, 133)	A decrease was any decrease in the number of social activities as defined in Chapter 5. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between the number of social activities at intake and the number at the end of each 6-month interval.

Effects of Continued Care

<u>Outcome Class No.</u>	<u>Class Definition</u>	<u>Remarks</u>
#15	Patients who decreased the number of people to whom they talked daily during the study (72, 120)	A decrease was any decrease in the number of people to whom patients talked daily as defined in Chapter 5. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between the number of people to whom patients talked at intake and the number at the end of each 6-month interval.
#16	Patients who decreased their personal interaction during the study (60, 139)	A decrease was any decrease in the number of categories of people with whom patients interacted, where the categories included spouse, other relatives, and friends as defined in Chapter 5. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between the number of categories at intake and the number at the end of each 6-month interval.
#17	Patients who increased their economic dependence during the study (46, 164)	An increase was any change to a level of greater dependence as measured by the four graded classes of the Index of Economic Dependence defined in Chapter 5. Excluded from analysis were those who died and those for whom information was insufficient. For interval analyses, the comparison was between dependence rating at intake and dependence rating at the end of each quarterly interval.
#18	Patients who were admitted to nursing homes during the study (61, 177)	Patients who were admitted to nursing homes during the study, including those who later died, were counted as being in this class. Those whose nursing home status was unknown or who died without being admitted to nursing homes were excluded from analysis. For interval analyses, this class included all patients, cumulatively, who had been admitted to nursing homes at any time between intake and the end of each quarterly interval.
#19	Patients who were hospitalized during the study (171, 107)	Patients who were hospitalized during the study, including those who later died, were counted as being in this class. Those whose hospitalization status was unknown or who died without being hospitalized were excluded from analysis. For interval analyses, this class included all patients, cumulatively, who had been hospitalized at any time between intake and the end of each quarterly interval.
#20	Patients who were visited by a visiting nurse during the study (179, 98)	Patients who were visited by a visiting nurse during the study, including those who later died, were counted as being in this class. Those who died before being visited by a visiting nurse were excluded from analysis. For interval analyses, this class included all patients, cumulatively, who had been visited by a visiting nurse at any time between intake and the end of each quarterly interval.

<u>Outcome Class No.</u>	<u>Class Definition</u>	<u>Remarks</u>
#21	Patients who were visited by a nurse other than a visiting nurse during the study (38, 255)	Patients who were visited by a nurse other than a visiting nurse during the study, including those who later died, were counted as being in this class. Excluded from analysis were those whose status with regard to such visits was unknown.
#22	Patients who were cared for in the home by other than nurses (173, 122)	Patients who were cared for by other than nurses during the study, including those who later died, were counted as being in this class. Excluded from analysis were those whose status with regard to such visits was unknown.
#23	Patients who were visited at home by a physician during the last 2 weeks of the study (22, 189)	Patients who were visited at home by a physician during the last 2 weeks of the study, including those who later died, were counted as being in this class. Excluded from analysis were those who died before the 2-week period or whose status with regard to such visits was unknown. For interval analyses, analagous counts were obtained for the last 2 weeks of each quarterly interval.
#24	Patients who had physician contacts during the last 2 weeks of the study (93, 118)	Patients who had any contact with a physician during the last 2 weeks of the study, including those who later died, were counted as being in this class. Excluded from analysis were those who died before the 2-week period or whose status with regard to such contacts was unknown. For interval analyses, analagous counts were obtained for the last 2 weeks of each quarterly interval.
#25	Patients who received services during the study from a dentist, eye doctor, optometrist, chiropodist, social worker, or physical therapist (118, 87)	Patients who received any of the indicated professional services during the last 2 weeks of the study, including those who later died, were counted as being in this class. Excluded from analysis were those who died before the 2-week period or whose status with regard to such services was unknown. For interval analyses, analagous counts were obtained for the last 2 weeks of each quarterly interval.
#26	Patients who died in a hospital during the study (48, 39)	Excluded from analysis were patients who were alive at the end of the study.
#27	Patients who were attended by a physician on the day of death (62, 25)	Excluded from analysis were patients who were alive at the end of the study.
#28	Fatalities on whom an autopsy was performed (21, 57)	Excluded from analysis were patients who were alive at the end of the study.

**APPENDIX:**  
**STATISTICALLY SIGNIFICANT TREATMENT EFFECTS AT END OF STUDY**

The significant results at the terminal point of the study are presented on the following pages. Each line in the list includes, in order, the Intake Class No. (defined in Chapter 14), the Outcome Class No. (defined in Chapter 14), and the numbers of treatment and control patients in the specific Intake Class according to the presence or absence of the indicated outcome. From each line of results, the following model table can be constructed:

Patients in specified Intake Class			
Indicated outcome	Treatment group	Control group	Totals
Present	<i>a</i>	<i>c</i>	<i>a+c</i>
Absent	<i>b</i>	<i>d</i>	<i>b+d</i>
Totals	<i>a+b</i>	<i>c+d</i>	<i>n</i>

The letters in the model table are defined as follows:

*a* = number of patients from the treatment group who were in the intake class and also in the outcome class,

*b* = number of patients from the treatment group who were in the intake class but not in the outcome class,

*c* = number of patients from the control group who were in the intake class and also in the outcome class,

*d* = number of patients from the control group who were in the intake class but not in the outcome class, and

*n* = total number of patients.

Included in the list are results defined as statistically significant at the 5 per cent level either by the Chi-square test or by Fisher's

direct method for calculating probability. Results which were not significant at the 5 per cent level by either test were considered nonsignificant in the text. The criteria used to determine which test to apply were:

*No test* was done if either *a+b*, *c+d*, *a+c*, or *b+d* was less than 4, or if *n* was less than 13.

*Fisher's test* was done if *n* was less than 20, or if *n* was less than 40 and the expected value for any of the four cells was less than 5.

*Chi-square test* was done in all other instances.

Intake class no.	Outcome class no.	<i>a</i>	<i>b</i>	<i>c</i>	<i>d</i>	<i>n</i>
1	19	95	46	76	61	278
1	20	145	4	34	94	277
1	28	11	10	2	15	38 <sup>1</sup>
2	19	30	11	20	19	80
2	20	47	0	18	18	83
3	20	39	0	8	27	74
4	4	4	44	13	40	101
4	20	59	4	8	49	120
4	25	36	12	28	22	98
5	9	1	37	7	34	79
5	18	5	35	15	31	86
5	20	53	1	13	35	102
6	4	3	35	10	31	79
6	20	45	3	3	41	92
7	20	48	3	10	35	96
8	7	2	36	9	34	81
8	9	4	34	12	31	81
8	20	50	1	6	40	97
9	20	62	3	14	41	120
9	23	6	41	1	46	94
10	19	26	10	18	19	73
10	20	36	1	2	34	73
11	20	62	3	14	44	123
11	23	6	41	1	49	97
12	20	36	1	2	31	70

<u>Intake</u> <u>class No.</u>	<u>Outcome</u> <u>class No.</u>	<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>	<u>n</u>	<u>Intake</u> <u>class No.</u>	<u>Outcome</u> <u>class No.</u>	<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>	<u>n</u>
13	9	1	26	10	25	62	34	19	12	4	4	11	31
13	11	6	20	16	16	58	34	20	16	0	3	14	33
13	18	1	26	9	27	63	35	20	8	1	1	12	22
13	20	36	0	5	31	72	36	19	14	7	5	12	38
14	10	14	24	23	12	73 <sup>1</sup>	36	20	21	0	4	15	40
14	19	74	31	50	47	202	37	20	10	1	1	15	27
14	20	109	4	29	63	205	38	8	0	20	5	18	43
14	24	40	35	27	48	150	38	14	9	8	5	18	40
14	25	48	25	34	38	145	38	19	19	9	10	15	53
14	26	25	14	13	19	71	38	20	29	0	6	21	56
14	28	9	8	1	11	29 <sup>1</sup>	39	3	0	16	7	20	43
15	9	8	68	19	63	158	39	4	0	16	7	20	43
15	20	98	4	16	76	194	39	9	1	15	11	16	43
17	7	1	22	7	22	52	39	11	1	15	10	14	40
17	9	1	22	7	22	52	39	20	20	2	2	28	52
17	11	4	18	14	13	49	40	9	2	9	11	6	28
17	18	1	22	7	22	52	40	20	12	1	3	15	31
17	20	30	0	2	27	59	41	20	46	0	11	12	69
18	14	9	9	1	18	37	41	24	19	11	4	16	50
18	20	31	0	13	14	58	41	26	11	5	2	9	27
19	10	10	18	18	9	55 <sup>1</sup>	42	14	9	2	2	7	20
19	19	47	21	30	29	127	42	20	11	1	3	7	22
19	20	67	3	14	46	130	43	5	14	20	5	23	62
19	25	33	15	24	25	97	43	6	5	32	0	28	65
20	14	5	6	0	10	21	43	20	51	1	13	22	87
20	17	6	6	0	10	22	43	24	20	14	8	20	62
20	19	11	4	5	9	29	44	13	6	62	1	81	150
20	20	15	0	4	8	27	44	20	94	3	21	72	190
21	20	78	3	11	66	158	45	7	0	31	6	24	61
22	20	20	0	11	8	39	45	9	2	29	9	21	61
23	20	19	0	5	7	31	45	11	6	22	13	15	56
24	20	31	0	11	13	55	45	20	34	4	8	25	71
25	20	55	3	12	37	107	46	20	53	0	11	27	91
26	19	26	10	16	17	69	47	10	10	22	21	14	67
26	20	40	0	15	16	71	47	14	15	20	6	37	78
26	24	14	11	6	17	48	47	16	13	21	7	35	76
27	20	44	2	7	33	86	47	19	39	15	29	30	113
28	20	36	0	10	9	55	47	20	58	0	15	42	115
28	24	15	9	4	13	41	48	20	60	3	5	42	110
29	20	7	0	2	5	14	48	24	24	18	16	29	87
30	20	43	0	13	11	67	49	20	85	1	29	52	167
30	24	15	13	5	15	48	50	5	16	35	6	41	98
31	20	9	0	2	6	17	50	20	70	1	15	38	124
32	3	7	24	1	24	56	50	25	32	18	18	27	95
32	20	49	0	16	15	80	51	14	19	29	12	47	107
32	24	17	14	7	18	56	51	20	75	3	19	56	153
33	20	11	0	2	6	19	51	22	33	10	25	21	89 <sup>1</sup>

Effects of Continued Care

<u>Intake</u> <u>class No.</u>	<u>Outcome</u> <u>class No.</u>	<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>	<u>n</u>	<u>Intake</u> <u>class No.</u>	<u>Outcome</u> <u>class No.</u>	<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>	<u>n</u>
51	28	11	15	3	19	48	61	28	7	3	0	5	15
52	9	3	32	14	36	85	62	20	57	0	10	38	105
52	13	6	29	2	48	85	63	20	70	3	12	40	125
52	20	48	2	14	40	104	63	26	15	5	5	9	34
53	18	4	33	14	26	77	64	20	25	0	4	14	43
53	20	50	0	13	30	93	65	7	0	23	5	9	37
53	28	7	5	1	10	23	65	20	29	2	6	9	46
54	19	30	15	11	22	78	66	19	36	16	22	23	97
54	20	47	2	7	24	80	66	20	56	1	10	33	100
55	5	18	29	2	28	77	67	2	8	8	5	21	42
55	20	63	3	14	24	104	67	20	15	0	6	17	38
55	24	27	20	10	21	78	68	18	4	33	15	29	81
56	11	5	22	15	20	62	68	19	35	12	27	22	96
56	20	45	1	10	35	91	68	20	51	0	13	34	98
56	25	23	5	20	17	65	69	9	10	56	21	49	136
57	20	37	0	10	34	81	69	20	94	4	21	60	179
58	20	88	3	20	39	150	70	14	25	42	12	65	144
59	5	11	17	2	17	47	70	19	74	28	54	48	204
59	20	40	2	11	13	65	70	20	105	4	27	67	203
59	24	18	10	6	14	48	70	26	27	13	13	20	73
60	17	17	41	7	54	119	70	28	8	7	1	13	25 <sup>1</sup>
60	20	79	2	16	56	153	71	3	8	21	2	27	58
60	25	39	19	25	33	116	71	20	36	0	6	25	67
61	20	24	0	7	24	55							

<sup>1</sup>Included in this line are patients observed only at the beginning and end of the study, since a concomitant

interaction effect was present between the observation process and the treatment program.

## INDEX

- Abington House, an intermediate hospital 16-17, 83  
background vii-x (Preface), 1-5  
classification 54-57, 68-70, 153-163  
    (See *measures*)  
    clinical diagnosis 54-55  
    clinical diagnosis and indicators of disease 56, 56  
    dementia 57  
    disability 55-56  
    disease-disability profiles 56-57  
    identifying social characteristics 68-69  
    indicators of disease 55, 57  
    intake classes 98-99, 153-159  
    psychological 51-52  
    outcome classes 102-105, 153, 159-163  
    social deprivation 69-70  
    social interaction 69
- design of experiment 5-6, 8-14, 46-48, 95-105, 107  
    (See *classification*)  
    (See *measures*)  
    basic plan of 8-10, 95-96  
    completeness of observations 47-48, 48  
    controlled study 8, 95-96  
    criteria for inclusion of patients 10, 17  
    data collection process 13-14, 46-47, 107, 108  
    death information, plan for 12  
    experimental effects 9-10, 96-98  
    experimental groups 8-9, 96-97  
    factorial design 9  
    intake classes, description of 98-99, 153-159  
    interaction effects 9, 9-10, 96-98  
    interval observations, plan for 11-12  
    interview process 46-47  
    nursing program 8, 9, 9-10, 11, 29-31, 96-98  
    nursing program effects 9, 9-10, 96-98  
    observation effects 9, 9-10, 96-98  
    observation schedule 107, 108  
    organization of staff 12-13  
    outcome classes, description of 102, 102, 153, 159-163  
    pilot group 10, 17  
    randomization, effectiveness of 98-99, 100, 101  
    randomization process 10-11, 95-96  
    reliability of outcome data 102, 102  
    simple intake 8, 10-11  
    sample selection 16, 17, 83  
    statistical analysis and interpretation 102-104, 105  
    terminal observations, plan for 12  
    treatment program (See *nursing program*.)  
    validity of experimental groups 100-102
- effects  
    (See *interaction effects*.)  
    (See *interval nursing program effects*.)  
    (See *observation effects*.)  
    (See *terminal nursing program effects*.)  
    (See *terminal nursing program effects, specified*.)
- generalizability 83
- intake classes 98-100, 100, 101, 153-159
- interaction effects 84-87  
    description of 80-81, 84-85, 86, 87  
    design for 9, 9-10, 84, 96-98  
    interpretation of 84-85
- interval nursing program effects 76-82  
    hospitalization 76, 78-79, 80, 81  
    house-confinement 79-80  
    injuries 76-77, 78  
    mortality 76, 77  
    nursing home admission 76-78, 79, 81  
    professional services 79, 81-82  
    social interaction 79-80
- measures 49-52, 109-152  
    (See *classification*.)  
    activities of daily living 50, 55, 57, 119-120, 146-148  
    care 52, 121-124, 137-144  
    death 50, 136  
    disease screening 49-50, 55-56, 56, 57, 126, 128, 130-132  
    Hollingshead Index of Social Class 51, 68, 109-110, 145  
    house-confinement 50, 120, 148  
    household composition 51, 69, 116, 118, 125  
    Index of ADL 50, 119-120, 146-148  
    Index of Economic Dependence 51, 68, 115, 117, 145-146  
    injury 50, 128, 137  
    intake measures 49-50  
    nursing activities 140-144  
    orientation and mental control 51, 135  
    permanent move 125  
    physical function 50, 55, 56-57, 119-120, 127, 129, 146-151, 150-151  
    principal diagnosis 54-55, 56, 56, 132  
    psychological 51-52, 133-135, 151-152  
    psychological adjustment 52, 133, 151-152  
    range of movement and strength 50, 127, 129, 148-151, 150-151  
    Raven Coloured Progressive Matrices 51, 134  
    social and economic 50-51, 69-70, 109-118, 137, 145-146  
    social deprivation 51, 69-70, 110, 112, 114, 115, 117  
    social interaction 51, 69, 111-114  
    social role 51, 68-69, 109-110, 115, 117, 137, 145  
    socioeconomic class 51, 68, 109-110, 115, 117, 145-146  
    summary of 49  
    walking 50, 120, 148
- methods  
    (See *classification*.)  
    (See *design of experiment*.)  
    (See *intake classes*.)  
    (See *measures*.)  
    (See *outcome classes*.)  
    (See *sample*.)
- nursing program in study 28-45  
    experimental design 8, 9, 9-11, 29-31, 96-98  
    frequency of visits 31-32, 32, 33-41, 42-44  
    nursing activities 29, 44-45, 140-144

## Effects of Continued Care

- patients visited 31-32, 31
- sustained visiting 32, 32
- visits in illustrative cases 43-44
- withdrawal from 42-44, 42
- observation effects 83-85
  - description of 83-84, 85
  - design for 9, 9-10, 83-84, 96-98
  - interpretation of 84
- outcome classes 102, 102, 153, 159-163
- purpose of study 5-6, 16
  - hypotheses 5-5
- results
  - (See *interaction effects*.)
  - (See *interval nursing program effects*.)
  - (See *observation effects*.)
  - (See *terminal nursing program effects*.)
  - (See *terminal nursing program effects, specified*.)
- sample 16-26
  - description at intake: age 18; sex 18; disease 18, 19; chronic disease abnormalities 18-20, 20; physical disability 20-21, 21; social and economic 21-25, 22, 24; psychological 25-26, 26
  - pilot group 10, 17
  - selection 16, 17
  - source, Abington House 16-17
- terminal nursing program effects 59-67, 71-75, 87-93, 164-166
  - (See *terminal nursing program effects, specified*.)
  - areas of measurement 59-60
  - function, injury, and mortality by age 71, 72
  - function, injury, and mortality for all patients 60
  - function, injury, and mortality by chronic disease abnormalities 60, 62-64, 64
  - function, injury, and mortality by diagnosis 60-61, 61, 52
  - function, injury, and mortality by disease-disability profiles 60, 61-62, 63
  - function, injury, and mortality by identifying social characteristics 71-72
  - function, injury, and mortality by sex 71
  - function, injury, and mortality by social deprivation classes 71, 72, 73
  - function, injury, and mortality by social interaction classes 71, 72, 72
  - infrequent outcomes 66-67
  - interpretation of 87-93
  - quantitative estimates 88-91
  - summarizations 60, 64, 66, 71, 73, 75, 88-91, 164-166
  - use of services by age 73, 73
  - use of services for all patients 64, 65
  - use of services by chronic disease abnormalities 64, 66-67
  - use of services by diagnosis 64-66
  - use of services by disease-disability profiles 64, 66
  - use of services by identifying social characteristics 73-74
  - use of services by sex 73-74
  - use of services by social deprivation classes 73, 74-75, 75
  - use of services by social interaction classes 73, 74, 74
- terminal nursing program effects, specified 60-66, 71-75, 88-91, 164-166
  - hospitalization 64-66, 65, 73-75, 73-75, 89, 91
  - house-confinement 71-72, 88, 90
  - limb movement 60-62, 61-64, 71-72, 72-73, 88, 90
  - nursing home admission 66, 74-75, 89, 91
  - orientation and mental control 60, 61, 62, 64, 71-72, 72, 88, 90
  - physician services 65-66, 73-74, 89, 91
  - professional services, nonphysician and non-nurse 66, 74, 89, 91
  - quantitative estimates, summarized 88-91
  - services at death 64-66, 74-75, 89, 91
  - social interaction 62, 71-73, 88, 90
  - walking 60, 61, 62, 63, 88, 90
- Visiting Nurse Association of Cleveland 28-29

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