The Care of the Long-Term Patient

National Conference

TO STUDY and make recommendations concerning health and other services needed by patients with chronic illness requiring continuous or prolonged care, the National Conference on the Care of the Long-Term Patient was held March 18–20, 1954, in Chicago, Ill. It was the second national conference to be held under the auspices of the Commission on Chronic Illness.

Scope and Purposes

Indicating the scope and purposes of this conference are the following excerpts from the keynote address by Leonard W. Mayo, chairman of the Commission on Chronic Illness and director of the Association for the Aid of Crippled Children:

"Though this has been designated as a conference on care, and though our mandate is to spell out the health and other services needed by those who are already ill, our basic concern is with prevention and rehabilitation. We focus on the problems of care because present services must be improved, extended, and effectively coordinated if more of the disabled are to be restored to productive living, the recurrence of long-term illness prevented, and the road to further research illuminated.

"For the purposes of this conference and the work of the commission, chronic illness has been defined as comprising 'all impairments or deviations from normal which have one or more of the following characteristics: are permanent; leave residual disability; are caused by nonreversible pathological alteration; require special training of the patient for rehabilitation; may be expected to require a long period of supervision, observation, or care.' The best estimates indicate that of the 5.3 million people in the United States who have a chronic disease or illness requiring long-term care, 2.1 million are 65 years old or over; 1.8 million are between 45 and 65 years of age; and 1.4 million are under 45.

"The more than 20 million people in the United States who have minor or nondisabling chronic diseases or impairments for which short-term care is generally available in most communities are excluded from conference consideration. Many of the recommendations that will be made by the conference concerning philosophy, methods of care, and coordination of facilities will nevertheless be applicable to this group in a general sense.

"The mandate given to the National Conference on Care of the Long-Term Patient constitutes a tall order. The official documents of the conference express it under five headings:

"1. Identify the requirements of the long-term patient in the various states and severity of his illness.

"2. Examine existing methods of providing care, explore new methods, and enunciate principles which should govern needed changes.

"3. Suggest patterns for desirable relationships between services, facilities, and programs.

"4. Recommend various ways to improve the financing of long-term care.

"5. Establish direction and suggest next steps for local, State, and national programs for the care of the long-term patient."

Organization

Reviewing the events which led up to this conference, Dean W. Roberts, M.D., director of the Commission on Chronic Illness, noted that the commission's 1951 conference on the preventive aspects of chronic disease dealt in detail with one aspect of the total problem. "The specifics of a comprehensive program for the care of the chronically ill are yet to be recommended," he stated. "In a sense, the 1954 conference on care of the long-term patient complements the 1951 conference on prevention."

Dr. Roberts described the organization of the conference, which he said has been different from previous ones, as follows:

"The membership of the Commission on Chronic Illness does not include the wide range of professional skills, experience, and knowledge necessary to properly think through the complex problem of care of the chronically ill. Therefore, this conference was devised to get technical help from experienced people from the entire country. Most of us have experienced the frustrations of trying to penetrate the interlocking problems of medicine, sociology, physical facilities, community organization, and finance. We needed help from many fields of endeavor . . .

"Twenty-eight study groups were organized to study limited facets of the problem, each of which included representation from several different fields. Among these were medicine, nursing, social work, occupational therapy, physical therapy, hospital administration, public health, public welfare, research, architecture, industry, and consumer groups. The various agencies through which care is financed were also represented, and most of the study groups included a member of the commission.

"The 28 study groups were organized into 5 conference committees representing the major areas of concern: (*a*) the patient at home, (*b*) the patient in an institution, (*c*) integration of facilities and services, (*d*) research, and (*e*) financing. Each study group was centered in a city which had had successful experience in the subject under study and where a nucleus of experienced persons were available. . . . In the past 10 months these small, specialized study groups have held an aggregate of over 60 meetings—some lasting several days—in 12 cities.

"In reality the conference began in the last week of May 1953 when the first nine study groups held their initial meetings in New York, Chicago, Boston, and Cleveland. The aim in the next few days is to digest the findings of the study groups and synthesize from them a series of principles and recommendations that will point the way for community action in the years immediately ahead. Many communities . . . are seeking the kind of guidance that can come from these deliberations."

Summary reports and recommendations of the five conference committees were published in the May 1954 issue of the *Chronic Illness News Letter*. Below are condensations of the speeches made by representatives of the organizations which sponsored the conference.

American Hospital Association

The American Hospital Association fully realizes that no type of institutional health care can be static. It must be adapted to changing needs which result from progress in medical science, extended programs in public health, and expanded emphasis on public welfare. It must contribute to the total health of all the people, and, most important, institutional services must reflect a forward look which anticipates new and important health service requirements.

The considered opinion of thoughtful leadership within the association is that the construction and operation of specially designed units of general hospitals for the care of chronically ill patients should be encouraged. We believe also that the formally organized, intricate services found in hospitals should be coordinated in an organic working relationship with the less com-

Presented for Edwin L. Crosby, M.D., executive director of the American Hospital Association, by Maurice Norby, deputy executive director.

plex service, or services, found in those separate institutions which are designed to serve patients having types of chronic illnesses not continuously requiring specialized services and equipment. We recognize not only that the provision of adequate care for chronically ill persons involves the establishment of facilities but also that their operation reaches deep down into the individual and public purse.

The realization of our mutual objective will require planning and financing. At present, the association, through two of its councils, is exploring needs in the chronic illness field with a view toward the development of an effective action program. This program, it hopes, will assist the many thousands of people engaged daily in activities designed to accomplish our common objective: better care for all the people.

We recognize our responsibility as an association to extend our efforts to all groups which can profit from our assistance. We are proud to have played a part in the coordination of interest and effort among medical, public health, public welfare, and hospital people through the organization, sponsorship, and support of the Commission on Chronic Illness. The American Hospital Association stands squarely behind the important programed projects of the commission, and it will assume its full measure of responsibility in this important work.

American Medical Association

PHR brief

The Commission on Chronic Illness has been most successful in focusing interest on problems concerned with chronic disease, in creating an atmosphere of cooperation, and in studying and devising methods for meeting the problems concerned with the care of the chronically ill.

By George Lull, M.D., secretary and general manager of the American Medical Association.

The American Medical Association considers three of the commission's activities especially worthwhile. The first is the National Conference on Chronic Disease held in March 1951. At that conference, experts from all fields concerned with chronic disease were gathered together for the first time. The conference proceedings, published by the commission in 1952, are invaluable in their contribution to any ultimate solution of the problems of prevention and detection of chronic disease.

The second activity is the *Chronic Illness News Letter*, published monthly by the commission. Its major contribution is its article in each issue describing the activities of a particular community, a particular movement, or a particular program.

The third activity is the present conference devoted to the care of the long-term patient. The commission has shown its ability to get together a wide range of professional knowledge from all parts of the country and to direct attention toward specific aspects of chronic illness.

The American Medical Association has been an active co-sponsor of the commission. It has, I believe, as great a stake in the success of the commission and of this conference as does any other group here represented. The medical profession is more intimately concerned with detection, screening, and the primary and secondary prevention of chronic illness than any other group, but it must share the responsibility for the care of chronically ill patients with many others in the health field.

While progress is being made in dealing with the preventive aspects of chronic disease, the problem of caring for those who are already ill is one that must continue to command our attention. Too often in the past, people have been prone to wave aside the problem of the chronically ill by saying, "They are a bunch of old people and they will have to be taken care of in an old folks home." Increased longevity has undoubtedly helped to increase the incidence of chronic disease, but it is not confined to aged people. Seventy-five percent of the chronically ill are in the productive years of their lives, under 65 years of age. It is with this group that the best results can be obtained.

A number of the chronic diseases, such as

high blood pressure, arthritis, kidney disease, arteriosclerosis, varicose veins, and chronic bronchitis, do not keep the person from carrying on some of the normal activities of life. Proper medical attention is essential in keeping such people busy with their daily routine, but for most of these people, the amount of medical attention necessary is very small in comparison with the attention they need from other workers in the health field. Let us hope that the physician, the dentist, the nurse, the hospital administrator, the health educator, and the social worker can work effectively together in greatly extending and improving the care of the chronically ill.

American Public Health Association

PHR brief

The American Public Health Association, which represents official and nonofficial public health agencies, is enthusiastic about this conference. Manifestly, chronic disease, or chronic illness, has become a public health problem.

Why do I say it has *become* a public health problem? Well, the sphere of the activity of public health at any given time, of course, is those fields in which the community as a whole wants or needs work done. In times past, the main emphasis was upon infectious diseases. Some of those infectious diseases—tuberculosis and syphilis, for example—are also chronic diseases. Mental illness, long a concern of the community, is also a chronic illness. Thus, chronicity is not new to public health. The particular chronic diseases which are now the major concern, however, are new.

How public health has changed its attitude concerning chronic diseases in response to community needs can be illustrated by the experience in Massachusetts in the 1920's. For 10 years, the Massachusetts Legislature asked in an informal way that the department of health of the Commonwealth do something about cancer, but the department during that period felt that cancer was not properly a concern of public health. Finally, the legislature ordered the department of health to do something about cancer, and no more nonsense. As a result of this order, the State now has a cancer detection reporting and treatment program which is one of the finest in the country. So far as treatment is concerned, the program consists principally of running a State hospital for indigent cancer patients, which is not only a fine institution for medical care, but is also a major research center. The latest development in chronic disease in Massachusetts is the construction of the Lemuel Shattuck Hospital of 500 beds. It will be opened shortly under the direction of the Massachusetts State Department of Health.

The public health department must respond, and it will respond, to the needs with which the community decides it should be concerned.

By Dean Clark, M.D., chairman of the Subcommittee on Medical Care of the American Public Health Association.

Public Health Contributions

Public health is much involved today in the field of chronic diseases, as demonstrated, for example, by the fact that 40 percent of the home visits of public health nurses from health departments are for chronic disease patients. The questions of how it is involved, how it should be involved, and how it best can use its particular skills in this field remain to be answered.

It seems to me that public health can offer some contributions which are almost unique. Public health traditionally has had an interest in health, as distinguished from disease, that can result in an emphasis in chronic disease programs on early detection, early diagnosis and treatment, and early rehabilitation. Its broad perspective emphasizes not a particular chronic disease or even a particular group of chronic diseases but, rather, the common denominator of chronic diseases.

If one considers the history of the control of tuberculosis and the skills that have gone

into that, one can see very quickly how public health can contribute, and is now contributing, to the control of other chronic diseases. Prevention is one of these skills. Not all chronic diseases, as we know them now, can be prevented, but many measures can be taken toward the prevention of a number of these diseases. The skills of case finding and recording and of mass diagnoses support the early detection of chronic diseases. Skills developed in the areas of institutional care of patients, the supervision of their care at home, and the provision of nursing services and family service can contribute to the management of all chronic diseases. Rehabilitation is an illustration of another skill which can be translated into the field of many chronic diseases. Finally, skills in administration and in the integration of community effort can be applied to all types of chronic disease programs.

The job ahead is how best to put these skills to work. The American Public Health Association greets this conference with enthusiasm and confidence.

American Public Welfare Association

PHR brief

The American Public Welfare Association, one of the founders of the Commission on Chronic Illness, takes pride in this conference as a demonstration of the magnificent work done by the commission. Public welfare workers have long been cognizant of the need for preventing and controlling chronic illness and disability, and for providing good care to the chronically ill.

Chronic illness is no respecter of economic status. Chronic illness has such serious and widespread consequences in family disintegration and loss of earning power that, for both humanitarian and economic reasons, it is clearly the obligation of public welfare to join with other interested groups to seek the means of controlling chronic diseases and improving the condition of long-term patients.

Public welfare agencies encounter a variety of problems caused by chronic illness. As far back as the midthirties, the National Health Survey indicated that the incidence of chronic illness was considerably higher for families on relief than for the population as a whole. The need for public assistance itself frequently arises from illness or its sequelae. In the nationwide study of the aid to dependent children program, sponsored 2 years ago by the American Public Welfare Association, it was found that one-half of the families were dependent because of a parent's illness or death. A major but unknown portion of the recipients of old age assistance is incapable of productive employment because of chronic illness or impairment. By definition, all recipients of aid to the blind and aid to the permanently and totally disabled have long-term disabling conditions.

Public welfare agencies have a major responsibility for helping chronically ill recipients and their families to plan for their care. They often help in finding a nursing home, boarding home, or other institution suited to the patient's needs. The public welfare agency also offers, to supplement such counseling and referral services, the social casework services so many chronically ill persons need. Community responsibilities of some public welfare departments include inspection and licensing of facilities for the long-term patient, and administration of institutions providing long-term care.

Lacunae in Present Provisions

Public welfare departments, as they are confronted with the many problems of planning for care of the long-term patient, wish for better organization of home medical services for these patients; for improved long-term care facilities, public and private, for the patient who cannot be cared for at home; for adequate financing of all the services needed by those chronically ill persons who are dependent on public assistance; and for vocational rehabilitation services that will return to productive

By Loula Dunn, director of the American Public Welfare Association.

work the many disabled persons on the assistance roles.

The complex of interrelated problems involved in caring for the long-term patient makes it essential that we continue to pool experience and resources. There must be joint planning for the training of medical and nursing personnel, for the development of hospital and other institutional facilities for the chronically ill, for organized provision of home care, for agreement as to the functions and relations of Federal, State, and local public agencies, and of voluntary agencies. All must be focused on the patient, his problems and requirements.

Public Health Service

The programs of the Public Health Service related to chronic diseases and long-term illness have changed strikingly in the 5 years since the first meeting of the Commission on Chronic Illness. Two new institutes concerned with research in the causes of long-term illness were established: the National Institute of Arthritis and Metabolic Diseases and the National Institute of Neurological Diseases and Blindness. Last July, the Clinical Center, which is rapidly becoming the focus of research in the chronic diseases and in the clinical aspects of other causes of long-term illness, was opened. And, very recently, the Service's activities for the control of chronic diseases were merged in a Division of Special Health Services to emphasize services rather than specific diseases.

Programs and Facilities

In these 5 years, the Nation has experienced a sharp reduction in the death rates from tuberculosis and syphilis. Intensive work with reported cases of syphilis in each State can keep this one-time major cause of long-term illness suppressed. Tuberculosis experts in the States, in private hospitals, and in the Public Health Service are working toward combined home care and hospitalization programs; toward more efficient treatment; and toward intensive followup which will make the case-finding programs of earlier years yield the best results in tuberculosis control.

Through the National Hospital Survey and Construction Program, the Public Health Service also has been concerned with the planning and construction of facilities needed for long-term patients. This program has aided in the construction of 3,000 beds in chronic disease hospitals, 11,000 beds for mental patients, and 6,000 beds for tuberculosis patients. In addition, Federal grants have aided in the construction of 86,000 general hospital beds, a substantial proportion of which, as you all know, is absorbed by long-term patients.

President Eisenhower has recognized the close relationship between the problems of an aging population and the increasing demand for facilities for the care of long-term patients. He has discussed the need for increasing the Nation's supply of beds in chronic disease hospitals and nursing homes, as well as of diagnostic and treatment centers for ambulatory patients and rehabilitation facilities.

The President also has pointed out that vocational rehabilitation programs must be strengthened to return the disabled to useful, productive lives. His announced goal is to step up the annual number of rehabilitated persons from the present 60,000 to 200,000 during the next 5 years.

Two more important fields in which Federal agencies can be of particular assistance to the organizations and communities planning for care of long-term patients are health statistics and epidemiology. The source book prepared for this conference (Care of the Long-Term Patient, Public Health Service Publication No. 344, Washington, D. C., U. S. Government Printing Office, 1954) is a good example of this unique capacity of Federal agencies. Not only several Public Health Service divisions, but also various parts of the Social Security Administration and the Office of Vocational Rehabilitation, as well as the numerous organizations participating in this conference, have

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By Leonard A. Scheele, M.D., Surgeon General of the Public Health Service.

assisted. For many years, a troublesome handicap to planning and to distributing resources effectively and economically has been the lack of reasonably adequate guides to the size and characteristics of the problem. The source book does not pretend to have all the answers, but it assembles the best available data.

Stake in Conference Objectives

In every phase of its mission, the Public Health Service has a stake in the objectives of this conference. Our research programs are dedicated to the discovery of new and more effective ways of caring for patients with long-term illnesses. Our public health programs are devoted to aiding State and local agencies, both private and public, in the development of community programs that will provide effective services of the types demanded by the particular problems of long-term patients.

When the Commission on Chronic Illness was established, the sponsors confidently expected that a voluntary partnership of the major professional organizations concerned with the problem would stimulate parallel activities in many other groups. Our expectations have been realized; in some instances, dramatically.

The 44 voluntary health agencies and governmental agencies participating in this conference are dramatic evidence of the growing interest and progress in the field of chronic illness. Some of the agencies were not in existence or were only in embryonic stages 5 years ago. The financial support of this conference by four leading insurance companies and the Rockefeller Foundation is dramatic evidence that chronic illness is a problem of the first importance to our Nation.

In the past 5 years, we have learned a great deal more about the problem. Many organizations and communities have acquired successful, real-life experience in providing essential services for the chronically ill. We are beginning to see in clear outline some aspects of the total problem that earlier seemed to be vast and shapeless. In sharing our knowledge and experience and in studying together the newly revealed phenomena, the members of this conference have a wonderful opportunity to push forward once again the line of battle against chronic illness and its tragic consequences.

Other Participating Organizations

In addition to the five organizations which sponsored the Conference on the Care of the Long-Term Patient, the following voluntary and governmental agencies participated:

American Academy for Cerebral Palsy
American Academy of General Practice
American Association of Medical Social Workers
American Association of Nursing Homes
American Association of Psychiatric Social Workers
American Cancer Society
American Dental Association
American Diabetes Association
American Dietetic Association
American Heart Association
American Nurses Association
American Occupational Therapy Association
American Physical Therapy Association
American Psychiatric Association
American Psychosomatic Society
Association of State and Territorial Health Officers
Bureau of Public Assistance, Social Security Administration
Children's Bureau, Social Security Administration
Community Chests and Councils of America
Industrial Medical Association
Muscular Dystrophy Associations of America
National Association for Mental Health
National Association for Practical Nurse Education
National Association of Registered Nursing Homes
National Conference of Rehabilitation Centers
National Epilepsy League
National Foundation for Infantile Paralysis
National Health Council
National League for Nursing
National Medical Association
National Multiple Sclerosis Society
National Rehabilitation Association
National Social Welfare Assembly
National Society for Crippled Children and Adults
National Society for the Prevention of Blindness
National Tuberculosis Association
Office of Vocational Rehabilitation
United Cerebral Palsy Association
Veterans' Administration