Patient Services in Chronic Diseases

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THE HEALTH and medical care resources and facilities generally available in our country were developed in response to the demands of acute illness. It is now inevitable and desirable that these same resources be directed toward the demands of chronic illness, which has become the main preoccupation of those in the public health and medical care fields. In determining the changes in philosophy and facilities which our medical resources must undergo to deal with this new problem, it may be worthwhile to contrast the characteristics of the acute illnesses which have occupied us in the past with those of the chronic illnesses which will occupy us in the future.

The most obvious characteristic of acute illness is dramatic onset. The healthy individual develops signs and symptoms such as sharp pain, high temperature, or coughing of blood which make clear to the patient, to the family, and to the physician that serious illness is present. In acute disease the length of illness is usually brief, most often measured in days, and the illness is marked by a crisp, definitive end point. Most often the patient makes a complete recovery, returning to good health and the activities, pursuits, and responsibilities which characterized his life before the acute illness. The characteristics of most serious chronic diseases are so different as to be almost the obverse side of the coin.

The onset of many of the chronic diseases is so insidious that often the individual will not clearly recognize that there is anything seriously wrong with him. There is no qualitative relationship between the presenting symptoms and the severity of the underlying disease. Diabetes is a very serious illness whose sequelae are disabling and often deadly. We are all familiar with the damage to the cardiovascular system which leads to heart disease, kidney failure, gangrene of the extremities, blindness, and other complications of diabetes, and yet it is commonly stated that more than a million Americans who have the disease are not aware of it. The reason is obvious; the initial symptoms may present such small deviations from the normal that neither the patient nor his family knows that anything is seriously wrong.

By definition the duration of chronic illness is measured not in days but in weeks, months, and years. Again in distinct contrast to acute illness, chronic disease usually does not have a sharp end point with complete recovery; more often disability and handicap remain for life.

The problems that face the individual, his family, and society in the care of the chronically ill are due to insidious onset, long duration, and disability.

Medical Problems

To determine the kinds of hospital and related facilities required for the care of the chronically sick, we should closely examine the medical, nursing, and other areas of patient need. The view of chronic disease held by the general public and even by some physicians is colored by a number of misconceptions such as: chronic disease is indolent; not much can be done for a chronically sick person; the chronically sick can be cared for in lesser facilities; not as much or as high-quality doctors' care is needed for the chronically sick as for the acutely sick; the most costly and complex resources are needed by the most acutely sick and

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not by the chronically sick. These views lead to the greatest misconception of all—that good care for the chronically sick is cheap.

These erroneous impressions have arisen because we have tried to lump together all chronic disease in the same way that we generalize about all acute disease. The difficulty lies in the fact that, for medical care purposes, acute illness has only one stage while chronic disease has several. These are, first, the active or acute phase which requires definite diagnosis and the application of definitive therapy, and, second, the rest of the natural course of the disease.

When we discuss medical care needs, facilities, personnel, and costs we must specify whether we mean the active, acute, first phase, with its great demands for highly skilled physicians and many other professional and technical people and resources, or the second phase, with its lesser demands on facilities and personnel and, therefore, lower cost.

When a chronic disease hospital has low per diem rates, 1 of 2 circumstances prevail: if the patients are really sick enough to require hospital care, then they are not getting the kind of medical care they require; if the patients are getting the care they need at this low cost, then their needs must be primarily nursing or custodial, and the use of the term "hospital" is misleading. High-quality, intensive hospital care for the active phase of chronic illness costs at least as much as care for the acutely sick. The reason is clear. In order to determine or apply definitive therapy it is necessary to establish an accurate diagnosis. The diagnosis of chronic illness requires the most complex laboratory facilities, the widest range of procedures, and the most difficult and expensive X-ray examinations. For example, the X-ray procedures for diagnosing lobar pneumonia and fractures of the long bones are simple compared with those necessary to diagnose a congenital abnormality of the heart or a tumor of the brain.

Diagnosis, particularly in older people, is also difficult, because often more than one important diagnosis is involved. It is not uncommon that a patient with a tumor of the bowel may also have atherosclerosis, hypertension, or other such complications.

The same complexity prevails in the application of definitive therapy. When a healthy person is suddenly struck down with an acute illness, the treatment is often obvious, and the patient's undiminished resources can be relied upon to help him through the period of acute stress and illness.

But a patient with chronic disease is likely to be older and more debilitated and beset by complicating conditions. For example, operating for carcinoma of the bowel on a patient in his fifties or sixties requires particular care in the use of anesthesia because the patient's vital capacity may be less than it once was. His heart and blood vessels are not as supple as they were, and this must be considered when it is necessary to replace body fluids. Injudicious use of blood and fluids can lead to acute heart failure in a patient undergoing such major surgery.

In our experience at Montefiore Hospital with the complicated surgery needed by patients with chronic disease, whether it be surgery of the lungs, abdomen, or heart, we find it essential that physician anesthetists be used because such operations are always difficult and the patient's hold upon life is so delicate.

The need for the most expert skill applies equally to the surgeon, the internist, and everyone in the specialties and subspecialties of medicine. Chronic disease batters and beats its victims. All too often we first see the patients when the disease is well along, or on a second or third or even tenth or twelfth hospital admission. Their persons, their tissues, their spirits must be handled by the most gentle and the most proficient.

The requirements of great skill also extend to nursing. Without good nursing, a patient with a neurological disease or a fractured hip can become a patient with bedsores or infections which threaten his life or at least his well-being. The nurse's responsibilities include maintenance of the patient's nutrition, carrying out complex treatments, participating in the rehabilitation of the patient, utilizing the special relationship to encourage the patient in the difficult adjustment to serious illness, and many more such vital tasks. These make the care of the sick, debilitated patient with

chronic illness the greatest challenge that nursing, with its skills, understanding, and compassion, has ever been called upon to face.

Readjusting

A serious difficulty accompanying long illness and disability is the impact of the illness upon the patient's relationships with his family and with society. Most families do not have either the financial or emotional resources to withstand the onslaught of chronic disease without help. We must recognize that chronic illness not only tends to pauperize our families but also has a destructive effect upon the family structure. Therefore, we must deal with the personal and familial emotional and social aberrations which accompany every serious long-term illness.

Here is a typical example of these difficulties. A 50-year-old man, the head of a family and the breadwinner, develops abdominal symptoms, goes to the hospital, is operated on, and is found to have a cancer of the bowel with some spread. This man not only has his life threatened by illness, but after his period of hospitalization, he is going to be handicapped and ill for the remainder of his life. Instead of being the leader and provider he will have to be cared for and provided for.

This is not only a personal catastrophe, but a catastrophe for the entire family. His wife has to assume responsibilities which he formerly bore. His children, for whom he had great hopes and aspirations, can no longer continue with their schooling but must help the family in its difficulties. One day he is a father, husband, leader, producer, giver; several weeks later the entire social structure built up over a long period of time has been shattered.

Anyone who has cared for the chronically sick has seen patients whose greatest lack of well-being, whose suffering and discomfort came, not from the physical pain and the illness which might ultimately destroy them, but from the disordered situation which the illness has produced within the family.

We physicians concerned with hospital and medical care cannot narrowly define our responsibilities as we might like to. We must define our responsibilities to fit the patient. Since the social and emotional effects of long-term illness are vital to the well-being of the patient, the family, and the community, we must concern ourselves with this kind of problem just as effectively and aggressively as we do with organic medical problems. The social worker with her special training and skills can effectively join with the physician to meet this important patient need. The general hospital will have to broaden its philosophy and resources to deal with this aspect of illness.

Special skills are needed in medicine, physical medicine, psychiatry, social work, nursing, vocational rehabilitation, speech therapy, and many other areas to enable the patient to make the maximum use of his remaining physical, mental, and emotional resources. This concept of patient care has recently gained recognition. Every general hospital, nursing home, and home care program should undertake the rehabilitation activities appropriate to its patient population.

Among the many other activities that we must undertake in caring for patients with chronic illness is occupational therapy. This can be a very important tool if it is utilized in an intelligent manner and is integrated with other medical care. It is sad to realize that the first extended period of leisure which some people have ever had has been enforced by serious illness. In our own experience we have found that skilled occupational therapists, warm, interested, and willing to find out what kind of person the patient is, what his interests are, and the directions in which his talents or desires lie, can help patients to find the wellsprings of creativity which exist within so many people unknown to themselves or others. This discovery adds a new dimension to the sick person's life and makes him feel productive and worthwhile.

Other services, such as recreation, vocational training, counseling, and job placement, are also required.

Community Program

In all communities we face the need to modify, change, and add to existing resources, facilities, and services so that we can adequately serve the chronically sick. I recommend that

you who are concerned with planning for the care of the chronically ill in a community close your eyes and dream this dream: Your community has no facilities for these people, and you can have any you believe necessary.

We all know that we will wake to the reality of facilities in the wrong place or of the wrong kind, and we must work and live within this reality. However, this exercise of imagination has concrete value. It is essential that the planners in every community have a blueprint, a dream, in keeping with the town's own cultural characteristics, needs, and resources, to show them where they should be going. Then as opportunities present themselves, they can move toward this ideal with a logical, planned program.

What are the facilities a community needs to care for the chronically sick?

1. A good general hospital with a broadened philosophy, providing not only doctors' care and nursing service but the services of social workers, and facilities for recreation, rehabilitation, and occupational therapy. In this hospital patients are not classified as acute or chronic but are cared for as their needs match the hospital's resources.

The hospital patient is a patient who requires definitive diagnosis and definitive therapy. Any patient who does not fit these criteria must be cared for elsewhere. This practice will insure that the hospital bed is used for its stated purpose. In effect hospitals should be, in toto, intensive care units. This can be brought about only by providing other institutions to which patients can be transferred when they need medical and nursing care less extensive and intensive than that provided in the modern general hospital.

2. A home care program for those patients who still require medical, nursing, and related care but who no longer require the specialized resources of the hospital. In the Montefiore Hospital home care program we have, by design, selected only patients who are quite sick, and for them we emphasize the role of the physician, the nurse, and the social worker in caring for them. We have recently undertaken, in conjunction with the Beth Abraham Home, a custodial institution, a somewhat different type of home care program for custodial patients. The emphasis and major cost of this program center around housekeeping and homemaking services rather than doctors and medical care.

3. The nursing home, preferably on the grounds of the hospital and certainly under the hospital's auspices for medical care and medical care supervision. This is a facility where patients, after completing the active phase of hospitalization, stay for days or weeks and receive the nursing care and, it is hoped, the aggressive rehabilitation designed to return them to the community.

4. A custodial institution for people who no longer belong in a hospital and yet cannot be cared for at home because of disabilities, handicaps, or social situations. This institution emphasizes nursing care and meets the daily needs of severely handicapped people. It would be desirable if it were on or near the hospital grounds, and certainly its medical care program should be under the supervision and direction of the general hospital.

5. An adequate outpatient department for those people who are sick but who can travel from their homes to the hospital. This activity should provide the kind of medical supervision and attention which will not only treat the immediate medical problems of these people but also will tend to keep them out of institutional facilities.

Summary

Chronic disease in its active, acute phase requires the high-quality, complex diagnostic and therapeutic facilities of the general hospital. Beyond this phase lies a varying period when lesser but continued medical, nursing, and related care is needed. A home care program, an outpatient department, a nursing home, and a custodial institution, preferably on the hospital's physical premises but certainly under its auspices, are required to meet these needs. Such broad responsibility should be assumed by the hospital because its medical and related resources are organized and available in a manner that can rarely be duplicated by lesser medical care facilities.