

| *An experience in interprofessional team action directed toward rehabilitation of the adult poliomyelitis patient.*

Social Considerations in Patient Management

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ANY prolonged illness which takes the young adult from his vocational preparation, from breadwinning or homemaking, and places him in the unaccustomed role of patient obviously makes great realistic and psychological demands upon the individual and his family. The degree to which equilibrium is disturbed depends on the interrelationship of several factors, namely, the nature of the illness, the age and personality of the patient, and the manner and degree of family and personal disruption created by the absence of the patient.

Medical management can determine, in part, whether the disturbance will prove catastrophic, leading to permanent, almost total, destruction of normal satisfactions for patient and family, or whether it will prove temporary, altering the pattern, yet not destroying the groundwork, for constructive living. Furthermore, the ability of the patient to utilize medical care to the maximum will depend on how adequately his

social needs are met. These are the reasons why hospital personnel are concerned with social needs.

We are especially alert to what we learn from working with any group of long-term patients because each experience becomes potentially valuable in planning the chronic disease programs of tomorrow. A focus on rehabilitation obviously will be necessary in these programs if they are to be constructive and no more expensive than necessary. Rehabilitation-slanted efforts require interprofessional team action, a method more easily praised than implemented and dependent for its success on medical leadership.

At Colorado General Hospital, a part of the University of Colorado Medical Center in Denver, the application of the multidisciplinary approach over approximately 10 years in working with poliomyelitis patients has yielded certain observations. Some may have wider applicability.

The hospital is small, having only 300 beds. It is tax-supported, and the only private patients there are those under circumstances of special need. The cost for these poliomyelitis patients, all adults, is paid by the National Foundation for Infantile Paralysis. This organization not only has made possible the financial support of the patients but has greatly aided the teaching activities. It has also encouraged a team approach, which was easily and naturally evolved through the stimulus of Dr. Winona Campbell, long-time director of

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the poliomyelitis unit, and, later, of Dr. James Stephens, the present director.

The Patients' Problems

In poliomyelitis the sudden onset, the need for isolation, the uncertainty regarding extent of paralysis, the respirator care in bulbar cases, and the community fear or panic during an epidemic create certain characteristic problems during the early stage. Later arise the problems connected with family, school, or job disruption, and anxiety as to the degree to which affected parts will respond to treatment.

Still later, among the dwindling group who remain in the hospital, arise the difficulties from monotony and vegetation, from the adjustment to being relegated to the status of uninteresting chronic cases after a dramatic period of great attention, from very deep fears about the future, and from competitive anxiety upon seeing other patients make faster gains.

Finally, whether patients with residual paralysis go home early or late, they have the problems of being discharged home crippled to a greater or lesser degree, to carry on with medical recommendations, and to take up the task of competing with normal people in the outside world.

Despite their similarity, each problem varies according to the patient. Let us look, for example, at what the sudden transition from full activity to respirator status meant to three individuals.

One patient, the mother of six children, one of whom was an infant, said that as she lay in the respirator all she thought about was that she had left the house for the hospital with only one bottle of formula mixed ahead for the baby. No one else in the family knew the formula.

Another patient said that one of his wife's best friends had died in a respirator 2 years previously, that he thought he would die and knew that his wife thought so too. His main concern was getting his mother to come from another State before his wife went to pieces.

The third patient, a waitress responsible for the support of her little girl, had been rushed to the hospital before she could make plans for the child. Because she could not speak, we did not even know of the child's existence until the

landlady telephoned that the little girl had no shoes. The mother could only shake her head and cry when the child was mentioned.

To need to depend for one's breath on something outside one's self is, indeed, the ultimate in dependence. It is not strange, therefore, that the patient who is rushed to an iron lung from the excessive activity which so often seems to precede onset is anxious about yielding up his life to the efficiency of a machine. The fear induced by even the rattle of an uneven caster is familiar to us.

This common reaction is highlighted by the feelings of a patient who unfortunately was in a respirator with faulty hatches which occasionally blew open, lowering the pressure so that he could not breathe or cry for help. The respirator was repaired as soon as the problem was discovered, but during his entire period in an iron lung the patient lay in a state of tension, listening for the clickety-clack of the hatch, particularly during the graveyard shift when a nurse came in the room only every 15 minutes. He said that he knew he would be dead 14 minutes if the hatch went out the minute after she left. The patient was actually traumatized by his experience and still has a lack of confidence in the chest respirator.

During the acute period of poliomyelitis the patient's uncertainty regarding the extent of paralysis which will develop is another common form of distress. Patients tell us that they wonder whether they will wake up the next morning with another limb paralyzed. They describe nightmares of finding they cannot move at all.

One pretty woman, who felt insecure with her husband and who relied on her charms to hold him, had facial paralysis so that her eye and mouth were drawn down and she could not manage her tongue. She was horror-struck over her appearance. When she asked the physician how much farther the paralysis would go, he told her honestly that he did not know. She later described her anguish over what would happen next. She told her husband that he did not need to visit a "monster," and he told us that she offered to get a divorce.

Isolation adds its problems to the acute stage. During the period of fear, distress, and regression which illness brings, the patient needs the

warmth and reassurance of his family. Complete isolation not only sharpens his distress but heightens the family's panic. The physicians here have greatly lessened the number of overwrought patients and relatives by permitting relatives to come to the patient's door during the isolation period.

The Value of Social History

Lack of space prohibits describing the damage poliomyelitis causes to family ties and the reasons for a gradual deterioration of the patient's morale. Our concern in this discussion is how to prevent the panic and worries and family damage of the early stage, with their concomitants of irritability and uncooperativeness, how to obtain the earliest possible hospital discharge, how to prepare the patient for adjustment to his handicap constructively when he goes home. We have not found all the answers, and we do not always put into effect those we do know. However, there are certain things we have learned to do or not to do, and these I will describe.

From the beginning the patient must be understood as an individual and treated accordingly. Although the initial social history obtained from family members and the patient is often far from conclusive, it does afford a base from which the hospital team can proceed. Therefore, the history should be taken within the first few days after admission.

The nature of the epidemic slants the initial histories in that above all else the hospital beds must be kept cleared during the height of the season, and, if most of the patients are improving rapidly, we must know which of them has a suitable home to go to, which patients might be eligible for another hospital, and those patients for whom community planning must be begun immediately if the bed is to be released as soon as the patient is medically ready. Because time is too limited during these early days to permit individual exchanges of information among members of the team, regular conferences are held for all professional personnel. Pertinent information is shared at these conferences, and the plan for the patient's immediate future is decided.

The initial history provides information

about the physical setup of the home and an estimate of the capacities of the family to provide convalescent care and make arrangements for outpatient supervision and physical therapy. In addition the social history gives the medical social worker information about urgent family problems which she needs to take care of so that the patient is not needlessly harassed. The history provides an understanding of what the patient is worrying about. This insight will help personnel deal considerably with irritable or demanding behavior. If the worries are, as they so often are, about the patient's own condition or treatment, the informed physician can clear up the patient's misapprehensions and gauge his interpretations accordingly. Attention to the patient's problems and fears lessens the trauma of poliomyelitis to the patient. It makes him realize that the institution is genuinely interested in him and, therefore, that he can relax and trust the staff. Through the lessening of the patient's anxieties, the demands upon medical and nursing personnel become a little less.

Sensitivity in Management

The administration of the hospital vitally affects meeting the patients' social needs. For example, installation of a telephone system, which made it possible for patients to talk to their relatives, proved to be a most constructive measure in reducing worries. Relaxation of visiting hours permitted a great degree of personal security for patients and relatives. Secretarial service for group conferences, facilitating a flow of abstracts to local referring physicians and discharge recommendations to local health and welfare departments and national foundation chapters, helps to assure the continuity of care which is so essential but so difficult to maintain at a time when it is even more difficult than usual to handle routine paperwork.

The management of transferring patients to another hospital deserves special mention. The pressure for beds and of time tempts making a hasty arrangement in which the patient has not shared. The patient receives an abrupt reminder of his powerlessness over his own destiny if he is notified that an ambulance will take

him to another hospital within a few hours. Other patients, identifying themselves with their departing companion, may greatly resent their own helplessness.

This is the kind of destructive experience which leads to an eventual apathy or a sense of futility. Fearfulness over being moved, even into another ward, is evident in both adults and children with long-time disease and can only be accounted for by the transference of former associations of security to the particular bed or ward or respirator in which the patient is lying.

It is difficult for the patients who remain in the ward to see their former co-patients get better more quickly and leave. The interim months after the peak of the epidemic, when patients having some residual paralysis go home or transfer to another hospital, are particularly trying in several ways. This period coincides with the time when the nurses who arose to the emergency become bored with enemas and baths.

From the standpoint of the patient's mental health, expressions of hostility are welcome, and griping is not discouraged. However, as hostility is so readily attached to immediate objects, the nursing service and the food receive the greatest impact. The physician and the nurse in charge have a great responsibility of interpretation to the staff members who are in the direct line of fire.

While the physician and head nurse are coping with these problems, the medical social worker and the occupational therapist can also be of help to the patient. By getting the patient to talk out his feelings and by listening with understanding, the medical social worker can give support to the patient who despairs about his future. Encouraging the patient to use his good extremities in constructive occupation, which happens incidentally to work off some anxiety, and devising activities that will take the patient's mind off his troubles are among the contributions of the occupational therapist at this time.

Group recreation is very important although we are providing it in only a limited way. Until the advent of television, movies were the patient's first choice. Movies were so desired that our patients have taken up collections

among themselves to rent films in order to supplement the movies the hospital has been able to provide. Television now provides the most important outlet for escape from reality. Religious services have proved of great benefit to some patients, as have the individual visits of the chaplain and the ministers. Volunteers who provide either group entertainment or individual friendly visiting have also been of real value.

When the long pull sets in for the badly handicapped patients, the hospital encourages families to take patients home for weekends or holidays. These patients are given passes to leave the hospital as soon as their physical condition permits. This policy of weekend and holiday leave requires substantial sacrifice from nursing personnel because the patient must be dressed and undressed at odd hours, often the busiest or least staffed times of the day.

Although the patient longs to go home, his first visit especially may be very difficult. For the first time, he goes up his own sidewalk and stairs as a cripple, rather than as a fireman or an electrician striding home for supper or as a mother with her arms full of groceries. However, the gradual adjustment to the outside world during hospitalization makes the eventual discharge much less difficult for the patient and less fearsome for the family. The trips outside have helped break the monotony. Most of all, they have helped the patient remain part of the family group.

The feeding of patients who have paralysis of the upper extremities is another management problem bearing on the patient's eventual adjustment. And more, it is a practical problem of no small magnitude. The patient should be fed when the tray arrives. Like being moved without warning, for one to lie watching the hot soup grow cold and the grease congeal around the meat is a dismal reminder of complete helplessness. To be fed like an infant is bad enough.

Planning Vocational Rehabilitation

Early vocational rehabilitation planning is another constructive measure which can be employed. The mills of vocational rehabilitation grind slowly so that aptitude testing and initiation of forms and counseling service need to be

set in motion early. Doing something or reading something which the patient feels is directly related to earning a livelihood after discharge brings much stronger motivation than activities which are busy work or amusement.

Furthermore, the successful vocational rehabilitation of the handicapped person is the greatest single process in restoring his means of earning money, having a daily occupation, and usefulness to his family, thereby achieving self-esteem and the respect of others. The remarkably ingenious talents of the physical therapist and the occupational therapist can be made to count if the occupational goal of the patient has been established long before he leaves the hospital.

Patient-Physician Relationship

Of all the measures which are employed to sustain and develop the morale of the long-term patient, an almost intangible one, but calling for deliberate action, is that termed supportive help. Morale is basically a matter of self-esteem. A philosophical maturity not ordinarily encountered in the young is required before people are capable of separating the value of personality or self from that of the beauty and usefulness of the body. The equating of physical worth with personal worth must be broken down if the patient is to value himself sufficiently to make the tremendous efforts which are and will be required of him.

We are indebted to those who have worked with other diagnostic groups, notably cancer patients, for the knowledge that one can help a patient make the separation of inherent value of body and personality by utilizing the knowledge that most people place upon themselves the value that other people place upon them. If, by the actions and attitudes of others, a patient is made to know that he is a valued human being, worthy of sustained consideration and interest, it does much to lessen his feeling of worthlessness. All hospital personnel do contribute, positively or negatively, to the patient's attitude toward himself.

The physician's role is particularly significant. The patient may be especially attached to a particular nurse or physical therapist, and it is the medical social worker's special job to

give the patient support. However, there is no one who has the meaning to the patient that the physician has. The doctor's small acts or words take on far greater importance to the patient than even the doctor may realize. In a teaching hospital this may pose a problem more serious than is readily apparent. The chronic patient lacks medical interest, and the intern or resident or staff physician who was so interested in him when he was acutely ill now may pass him by.

The change of resident physicians or transfer of the patient from an internist to an orthopedist, although intellectually comprehended as part of the system, may actually seem to the patient desertion by his most cherished friend, although the word "friend" does not connote the combination of dependency, veneration, and desperate hope which go into a paralyzed patient's feelings about his doctor. Knowing perhaps the reasons for the casualness which social workers sometimes display in transferring patients to other workers, I am aware that the physician may feel embarrassed or think he is being egotistical to consider how much he means to the patient. The doctor may not realize that it is not he as an individual but rather what the patient has vested him with that makes him so important.

The value the physician seems to set on the patient becomes to the patient a measure of his own worth. Because the patient must sustain a feeling of personal worth if he is to strive, the efforts of our sensitive physicians in going beyond the line of duty to show their continuous interest in the patients have been of immeasurable value.

Planning for Discharge

Discharge planning for the badly handicapped patient must be begun a long time before the patient is to leave. Suitable housing will be the most difficult need. If the patient will require a nurse, there must be room for her in his home. Arranging for a housekeeper or practical nurse is a time-consuming task. Financial resources usually cannot be secured quickly. The patient's long-time participation in working out details with the worker and his family helps his adjustment to the frightening

matter of leaving the haven of the hospital. The long planning also helps the family ready themselves psychologically. Severe disruption in family life can take place during the long absence of one member. If this has not been prevented or if it has been augmented, as sometimes happens, discharge may be very difficult to work out.

With a respirator patient particularly, obtaining and financing equipment may be another long-time matter. Any hospital without a medical social worker is practicing poor economy in respect to discharges because the majority of patients and families must have help in planning and carrying out discharge arrangements. Finally, it should be said that hospital discharge merely ends one phase of the patient's social needs. Before he leaves our care some professional person or persons in his own community must be found to help him with the difficult problems that lie ahead.

In conclusion, our goal with poliomyelitis patients is to send them home as quickly as possible and to send them there as fit as possible to meet the problems which await them. To do this, we must try to understand the patient as an individual and to adapt medical management accordingly. Social needs warrant not only the concern and activities of the medical social worker but the joint effort of the entire hospital staff as well. This joint effort is promoted by regular conferences in which all concerned with the patient's treatment share information about and decide on plans for his individual care. Our common effort is directed toward reducing worry, preserving family strength, reducing reminders of helplessness, providing mental stimulation, encouraging gradual adjustment to the outside world, sustaining the individual's belief in his own worth, and promoting early vocational and discharge plans.

New Aramite Tolerance

The Food and Drug Administration announced on October 3, 1955, a permissible tolerance of 1 p.p.m. of the pesticide chemical Aramite for 19 food crops.

The tolerance level applies to apples, blueberries, cantaloupes, celery, cucumbers, grapefruit, grapes, green beans, lemons, muskmelons, oranges, peaches, pears, plums, raspberries, strawberries, sweet corn (kernels, but not forage), tomatoes, and watermelons.

Commissioner George P. Larrick said no residue of the pesticide, however, would be permitted to remain on forage crops such as alfalfa. This is in line with FDA's policy that milk should be kept free of any pesticide because of its dietary importance to infants and invalids.

The tolerance level was set under a new law requiring the Department of Health, Education, and Welfare to determine what amounts of pesticide residue can safely be permitted to remain on food crops.