Uninterrupted Care for Long-Term Patients

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IN JUNE 1960 Mrs. X suffered a cerebral vascular accident which resulted in paralysis of her right side and mild aphasia. She was immediately hospitalized in a comprehensive care unit where she received intensive rehabilitation services. Three months later, discharged as able to function independently in her daily activities, Mrs. X was walking with a cane and was considered rehabilitated within her maximum capacity.

During the succeeding months at home, however, Mrs. X lost interest and regressed to dependence on her husband and son for most of her care (for example, dressing, getting out of bed, walking) and her care became increasingly difficult for them. Hospitalization again seemed imperative. She refused to go to a nursing home and a homemaker service was not available. Because private hospital care was now financially prohibitive, Mrs. X, encouraged and assisted by the local county welfare worker, requested admission to the University of Minnesota Hospital Rehabilitation Center. Hence, after 6 months at home, it was necessary to again admit Mrs. X to another comprehensive care unit as a bed patient.

Could this second hospitalization within a year have been avoided? Was lack of therapy at home the reason for Mrs. X's regression? Were there social and emotional factors which had not been recognized during the initial rehabilitation that hindered the home program? What was the policy for followup care of patients from the hospital? Should there be a policy for continuity of care as a part of the hospital program?

These same questions are being asked by medical, nursing, and other disciplines in hospital units serving patients with long-term illness. The followup care of cancer patients as well as those with neurological, orthopedic, and cardiovascular impairments is becoming a major concern in comprehensive care services today. The need for prolonged medical management of patients who have been discharged from comprehensive rehabilitation programs has long been expressed by personnel providing these services in order to assure that the patient will be maintained at his optimal functional level.

In one followup study which demonstrated this need, 23 patients, all with a diagnosis of cerebral vascular accident with residual hemiplegia, were selected to be interviewed in their home environment. Each had achieved his maximum potential as determined by the rehabilitation team at the University of Minnesota Rehabilitation Center (*1*).

This study revealed that these patients had many unmet needs. First, definite gaps existed between the hospital care and instructions for home care of the patients. Second, public health nursing referrals were not being made to the extent that they should have been. Third, the patients' families were not involved in the early care of the patients nor were they aware of the patients' accomplishments in self-care and independence at the time they were dis-

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charged. As a result of this study, it was concluded that a better plan for continuity of care must be developed in order to insure that each individual maintained his rehabilitated status.

Case Review

To illustrate the various aspects of such a program of continuity of care, the following case study of Mrs. X is reviewed. On her admission to the university center, Mrs. X was a 73-year-old, obese, unkempt woman with many complaints. She appeared content to lie in bed and without interest in her surroundings when she did not get the attention she desired.

Although Mrs. X was capable of independent activity, she was reluctant to do anything which might reflect recovery and she required constant encouragement. Consequently, it was difficult to work with her. Mrs. X lived with her retired 75-year-old husband and her son James, aged 45. James, an alcoholic, had also had a stroke and the patient's only daughter had died following a cerebral thrombosis 2 years before Mrs. X's cerebral accident. Mr. X was stout, nervous, and hard of hearing. When interviewed by the social worker on the day of Mrs. X's admission, he appeared confused by his wife's illness and fearful of the hospital setting.

When Mr. and Mrs. X were seen together they exhibited a great deal of hostility toward each other. Mrs. X had formerly been the domineering person in the marriage, and both were finding their changed roles equally hard to accept. Each had many complaints about the other and there seemed to be no point on which they could agree. With this kind of background in mind, what could the rehabilitation center team do? How might they include her husband and son in Mrs. X's rehabilitation program? How could they prepare them for her return home? How could Mrs. X be helped to maintain her rehabilitated status after discharge? These and many other factors were considered by the team in planning for Mrs. X's total care.

The procedure in the planning of Mrs. X's program is briefly related below.

The first step was to include the family early in the hospital program. As part of the ward admission procedure, Mr. X was asked to complete a home questionnaire which requested a detailed description of the home, number of family members, and health status of each; also, whether the person who would assume responsibility for the patient at home would be able to visit the hospital for instruction.

The second step was to request the county public health nurse to visit the home and complete an information questionnaire. Information provided to the public health nurse included the patient's diagnosis, disability, and the reason for hospital admission. This report was compiled by the ward head nurse as part of the admitting procedure and then sent to the social worker for review and mailing. Within a week, the public health nurse returned her report to social service with the following comments:

1. The family, Mr. X and the son, wanted Mrs. X at home but were anxious about their role in her care unless she learned to function more independently.
2. Mr. X would be the most likely person to care for the patient because of the son's physical disability and alcoholism.
3. Mr. X's general health was good despite moderate deafness and an ulcer controlled by medication.
4. Some home improvements would be needed, such as rearrangement of furniture to provide a larger walking area, improved access to the bathroom, and removal of scatter rugs.
5. The public health nurse reported that she had assisted Mr. X in the completion of the home questionnaire.
6. Another home visit during Mrs. X's hospitalization was planned to give further encouragement and interpretation to Mr. X and the son.

Thus, within a week of Mrs. X's admission to the hospital the following had been accomplished: a detailed description of the home had been obtained, the family had been helped to realize some of the problems, the nurse was aware of the patient's eventual return home, and the hospital was assured that Mrs. X would be visited regularly by the public health nurse following discharge. The information received from these two forms was shared with the rest of the staff so that they could plan the program to fit Mrs. X's needs when she returned home.

As a part of the total rehabilitation program, Mr. X was requested by the social worker to visit the center for two reasons. First, because it was recognized that Mr. X had many concerns and fears regarding his wife's illness which needed to be allayed, and second, to give Mr. X an opportunity to observe his wife accomplishing her self-care activities so that he would be sure that she could be independent.

Mr. X, on this first visit, had many questions regarding his ability to care for his wife at home, the regulation of her drug intake, and the feasibility of leaving her alone. The latter was of most immediate concern as Mr. X wanted to be able to go fishing. It was recognized that Mr. X needed to pursue his own interests, and he was encouraged to accept the offer of a neighbor who had volunteered assistance. With this support, Mr. X was able to become more interested in his wife's problems.

Mr. X was shown the rehabilitation center facilities, and he was able to observe his wife's therapy program. Because of his deafness it was often difficult for the therapists to ascertain how much he understood. Although he was delighted to see his wife walking in the gymnasium, instead of praising her, he said she should have been doing as much at home. Later, in the rehabilitation kitchen, he only commented on the awkward use of her right hand rather than how well she was doing. Mrs. X was hurt by his comments and stopped trying when he was present. With the conflict between the two so apparent, Mrs. X's future success at home seemed quite hopeless.

Mr. and Mrs. X were interviewed frequently during Mrs. X's hospitalization, together and separately. Casework services centered mainly on their relationships and how they could be improved. Efforts were made to help them understand and accept each other's needs. Mrs. X grudgingly accepted that her husband needed outside interests while Mr. X learned to give his wife some recognition for her efforts. Neither of them was able to view their son's problems realistically, and they refused to have him seen by the social worker.

In the week before discharge, Mr. X spent 4 days at the rehabilitation center observing his wife's therapy program. All the rehabilitation personnel emphasized Mrs. X's need for encouragement. With constant repetition of this fact and detailed instructions for home care, Mr. X's understanding increased. Mrs. X, in turn, realized that her husband knew what she could do and that he would expect her to continue these activities at home.

The discharge referral to the family physician was prepared during Mrs. X's last week in the hospital. This included the staff physician's recommendations for care with specific instructions regarding the patient's medication. The nurse's report summarized the patient's activities of daily living, her independence, eating habits, and special diet. The report also included the patient's techniques for hygiene, and bowel, bladder, and skin care. The patient's attitudes toward her program and her relationship to other patients and personnel were commented on. The social worker outlined a brief social history, the current problems facing the patient and family, and noted the other community agencies interested in the family. Copies of this referral were sent to the public health nurse and the county welfare department. The social worker also telephoned the public health nurse just before discharge so that she would be ready to make an early home visit.

Early awareness of Mrs. X's health problem and social situation gave the public health nurse the opportunity to plan the program she might follow with this family. After reviewing the discharge referral and the plan for care with the private physician, the public health nurse visited Mrs. X on the day she returned home. A controversy over pills had already arisen which the nurse helped the family to settle, to Mr. X's relief and Mrs. X's satisfaction.

At the time of the nurse's second visit, Mrs. X fell and insisted that she could not get up. However, she was instructed how to rise from the floor and with encouragement was able to do this. Although in the beginning several visits were necessary each week, the number was gradually reduced as Mrs. X gained more self-assurance.

Mrs. X returned to the hospital for a followup examination 2 months following discharge. Before this appointment a report was received from the public health nurse regarding Mrs. X's progress which indicated that Mrs. X was ready to accept the back brace recommended

while she was in the hospital. With this knowledge before her appointment, financial arrangements were made with the county welfare board for Mrs. X to be fitted during her clinic visit, thus avoiding the necessity for another appointment.

During the past 15 months the public health nurse has visited Mrs. X to support her in maintaining independence in her daily activities. Her family physician provides medical care. The family physician and nurse communicate frequently regarding Mrs. X's problems and progress.

Although the home environment has shown little improvement, Mrs. X has maintained enough independence to remain in her home, to care for herself, and to carry out her homemaking activities. It is doubtful that this would have been possible without the constant support, encouragement, and coordination of effort among the hospital personnel, the family physician, the public health nurse, and the county welfare board.

Discussion

Mrs. X's history points out the many needs of the patient with a chronic disease and residual disability. Even though the patient participates in an intensive rehabilitation program and reaches the maximum potential within his or her capacity in the rehabilitation hospital, returning to the home environment presents a distinctly different situation. The needs at home must be considered, the facilities evaluated, and plans made to insure the continuity of necessary care for each patient with a long-term illness.

The active participation of the family from the onset of the rehabilitative process is imperative if the patient is to be maintained in an optimal functional status at home. Without the understanding, willingness, and cooperation of family members, the patient may not progress to or maintain his maximum capabilities. When the family has not been involved, evidence from the study cited has shown that the patient may return to his pre-rehabilitated status and may even regress to total dependency.

The plan for continuity of care has been presented in the narration of the events in the rehabilitation of Mrs. X. Other patients and their families have benefited through the same plan for followup care. The family's interest in becoming a part of the team immediately upon the patient's admission has been demonstrated. The patients have responded because of the knowledge that their families are actively engaged in learning about their programs of treatment and how the members of the family can be of assistance when they return home.

The social service department, the psychiatrist, speech therapist, physical therapist, and other team members began participating early in the rehabilitation program. Regular conferences were planned with these team members during the patient's extended hospital stay for both the patient and the family.

The development of this program of care was stimulated by the observation that an effective plan for comprehensive followup care was lacking. The director and the personnel of the department of physical medicine and rehabilitation were stimulated to seek a satisfactory means of continuing supervision and contact with the patients who had participated in their rehabilitation program. Consequently, a committee was formed, composed of the heads of the different divisions within the department. Included were representatives from medicine, social service, nursing, and occupational and physical therapy. Three public health nurses represented the State, the local nursing agency, and the University of Minnesota School of Public Health. The purpose of the committee was to develop a plan which would promote the most effective continuity of care for patients discharged from the rehabilitation center to the community and to insure as nearly as possible the maintenance of the patient's maximum rehabilitation in his home environment.

The home questionnaire objectives were to include the patient's family in the program as early as possible, to determine the physical aspects of the patient's home, to aid the rehabilitation center team in planning the patient's program, and to request a family visit to the rehabilitation center for instruction and observation.

The families' response to this effort has been excellent. Approximately 90 percent of the questionnaires have been returned within 1

week. Many families assumed the responsibility for asking for an appointment to learn about the patient's program. In one instance, the welfare department agreed to pay overnight and transportation expenses for such a family visit, if no other funds were available.

The purpose of the information questionnaire was to obtain an evaluation of the patient's home environment, both physical and emotional, and to improve planning for the hospital and home program. The public health nurse received the questionnaire in the first week of the patient's admission to the rehabilitation unit. The continuity of hospital and home care was enhanced by the public health nurse's visit to the home within a week of the patient's admission. Her visit provided an opportunity for the members of the family to express to her their anxieties and other feelings regarding the patient and the concerns regarding the many other facets of long-term illness which had affected them. The public health nurse was able to inform the family regarding the care and treatment that the patient was receiving. There was early consideration of the problems related to the patient's return to his home. Previously undisclosed problems were recognized by the nurse and reported to the hospital personnel so that better planning could be made in the patient's and family's behalf. Sometimes another residence or nursing home care seemed a better plan.

The public health nurse has shown exceptional interest and enthusiasm in more detailed care of the patient with long-term illness. Her reports have revealed her competence to aid the hospital staff in maintaining a program at home and have stimulated an interest in more extensive use of the public health nurse to maintain supervision of rehabilitated patients.

The discharge referral report provides a complete picture of the patient's capabilities and limitations, his potential for further progress, and the activities and care to be continued at home. This has enabled the family physician and the public health nurse to have more knowledge and understanding of the patient, therefore, resulting in a more comprehensive service to the patient, his family, and the community.

Summary and Conclusions

A plan for continuity of care for rehabilitated patients after discharge from the hospital has been portrayed through the case study of one patient with residual hemiplegia following a cerebral vascular accident.

The early involvement of the family and the public health nurse in the patient's total plan of care has shown the effectiveness of such a program. Consideration for maintenance of the patient's maximum potential should be the responsibility of the hospital and the community. Lines of communication should be set up and activated if intensive and extensive rehabilitation programs are to be effected and justified. The efforts expended by the patient in overcoming severe disabilities and achieving independence after prolonged rehabilitation should not be lost through community neglect. The expenditure of time and effort by the rehabilitation team and of large sums of money by the family or community resource are justified only if the functional ability achieved is retained.

Providing a plan for continuing care is primarily the responsibility of the rehabilitation center or hospital service, and an effective plan might well be instituted as soon as the patient is admitted for care and treatment of a long-term illness. The multidisciplines engaged in comprehensive care must concern themselves with total care, which means preparation for home management at the beginning of the extensive program. If the family and the community are asked to participate almost immediately on the arrival of the patient to the hospital, the optimal goal of many patients may well be realized.

Although such a plan may not insure ultimate recovery for each patient, this comprehensive plan will help many patients to achieve maximum independence. The assets and liabilities of the patient and his family will influence, in the final analysis, each patient's potential.

REFERENCE

(*1*) Anderson, E. M.: A continuity of care plan for long-term patients. Amer J Public Health 54: 308–312, February 1964.