

LEARNING THE CONCEPT: NURSING IN CHRONIC ILLNESS

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IT HAS BEEN POINTED OUT on numerous occasions that one of the nursing skills needed in many areas is the minute-by minute assessment of the patient's state and the consequent adaptation of nursing care. Regardless of the patient's illness, he usually passes from a form of self-sufficient independence, to helplessness, and then to a gradually re-gained autonomy. One of the distinguishing features is the time taken by the patient to progress through these phases. A surgical patient, depending on the type of surgery he has undergone, moves through these phases over a period of days or weeks. An obstetrical patient, as has been described in a recent article, advances through all stages in a matter of hours.¹ A patient with a chronic illness may require weeks, months, or even years and in the end may still not regain a measurable degree of autonomy.

From a teaching-learning viewpoint, one is concerned that the student learn how to assess, set objectives, and make appropriate adaptations in the methods she establishes for the achievement of her objectives. To care effectively for patients, the student needs to nurse them in the different phases of their illness. This goal can be readily achieved for the surgical or obstetrical patient because of the numbers of such patients, the rapidity with which they pass through the phases of their illness or need for care, and their hospitalization throughout. The patient who has a chronic illness receives care in a general hospital only until he has advanced through the acute phase or during

an exacerbation of his illness. Because of the fragmentation of location where care is available, the student will see the various aspects of care of persons with chronic illness in widely separated experiences. To become involved in the whole concept of nursing in chronic illness, with its range of possible combinations of relationships, the student needs to unify the "bits" which make up such nursing by experiencing them in one situation within a brief time period, — necessitating rapid alteration of methods and strategies of nursing. Following on from this notion, the question then becomes one of identifying the essentials to be learned about the concept and the experiences which will facilitate such learning.

In this paper, I wish to discuss the experience Basic Nursing students have in the Fourth Year of their university program here. To assist students to acquire depth in understanding the patient's universe and skill in helping him cope with the problems of chronic illness, they have an experience with patients who are being treated for tuberculosis in a sanatorium. The two questions raised earlier will be discussed. First, I will describe the essentials to be learned, which were derived from our own cumulative experiences in nursing the chronically ill as well as from the literature. Secondly, I will outline the structure which is evolving within which students learn.

Initially a diagnosis of tuberculosis with subsequent hospitalization is accompanied by shock and drastic change from a person's usual routine of living. Not only need the student learn to appreciate the magnitude of this wrench, but also to understand the struggle the patient is undergoing in trying to retain a place for himself within his family, occupation, and his social life. Compounding the dilemma is the highly regulated, bureaucratized, and frequently impersonal conditions of the institution that tend to segregate him from his former way of living. This situation and the care he receives gradually result in a mutual disengagement between the patient and his former social ties. In our present way of caring for the patient with tuberculosis, the student needs to allow this disengagement to occur and to accept the accompanying mourning. In coping with this situation the patient's reactions fluctuate unpredictably, ranging from aggressiveness to the medical staff, family and other patients, to rather tense calmness and sullenness. In adapting her nursing care the student learns to recognize cues which indicate the patient's need to verbalize the bind he feels between his ambitions and his obligations to his family on the one hand, and the demands placed on him by the medical therapy regime on the other. This conflict consumes tremendous amounts of energy and soon the student appreciates the periods of exhaustion and

apparent defeat. Accompanying this crushed feeling is an apparent lack of interest in the very condition that has precipitated the patient's present situation. Therefore, the student learns not to promote discussion of the disease process and therapy until the patient exhibits signs that he is becoming concerned about these topics. When this occurs the student proceeds to help the patient acquire the understanding and necessary skills to combat the illness. This latter phase is not dissimilar to that displayed by patients in the acute phase of any illness.

As the patient's confinement continues, he becomes more aware of the long-term implications of his illness. Because the course of the disease process and its response to therapy is unpredictable and time-consuming, the patient can view the process as endless. His life and existence may become meaningless due to the cumulative effect of social deprivation and seeming lessening of life's purpose. Accompanying this sense of futility are a variety of patient reactions which necessitate modification of nursing care. Generally speaking, she sees that the patient is less dependent on her for interaction and more dependent on his fellow patients. She concludes that further explanations of disease and therapy and assistance in the activities of daily living are not effective means of nursing intervention at this time. During this phase the patient has considerable difficulty making any decision related to his life in the future. The student learns not to force the patient in this process, realizing that time to him is unlimited. Thus, the student paces her expectations to the changes in the patient. However, she is constantly alert to cues indicative of his readiness to move forward from this phase of illness.

As the patient's state of health improves, consideration needs to be given to what the patient will do when he leaves the institution. For most patients some degree of adjustment in their former way of living is necessary. Sometimes the patient has no home. At other times he has to secure different employment or learn a new skill in order to change his occupation. The greater the adjustment required of the patient, the more energy is needed to motivate him into assuming a more active role in planning for his discharge. The student sees that the family is very important at this stage in stimulating the patient and in sustaining his efforts. She also learns that the nurse assists in the patient's rehabilitation by mobilizing and co-ordinating the activities of the health team members to guide the patient and his family in their search for an acceptable plan. Thus, through involvement in the care of the patient at this phase of his illness, the student learns that preparation and rehabilitation is a co-operative effort of all persons concerned.

Any discussion of the structure within which the students learn the essential aspects of nursing in chronic illness needs to consider their experiences antecedent to that in the sanatorium. In an acute care center they nurse patients with multiple sclerosis, spinal cord injuries, and long-term renal conditions. In an out-patient chest clinic they work with patients who come for diagnosis, follow-up medical care, and assistance from the public health nurse and social worker concerning tuberculosis. Through visits to the homes of patients, students are able to see some of the ways that the family and the individual cope with the problems of chronic illness. These experiences enable the student to observe the patient's shock that occurs with diagnosis, the helplessness during the acute phase of his illness and the degree of autonomy as he recovers. Due to the fragmentation of time and place there is discontinuity in the student's concept of chronic illness. A short concentrated experience at the sanatorium with patients in different phases of the same illness in one setting allows the student to compare patient's reactions, bring together the knowledge previously acquired to make appropriate nursing responses and thus see nursing in chronic illness as a continuous process.

In the sanatorium, patients are assigned to a ward depending on the severity and phase of their illness. Because of the limitations of the clinical setting the students are divided into three groups. One group cares for patients who are in the initial, acute phase of illness. Since these patients need care with which the student is familiar, she does not require a long experience to learn to care for them. The other groups commence their experience with patients who have been in the sanatorium for some time. Some of whom are preparing for discharge while the discharge of others is still indefinite either because their recovery has not sufficiently advanced or because they have no suitable home to which to go. These patients require care with which the students are not as adept. In fact, they feel quite useless at first because the patients appear so self-sufficient. They have difficulty obtaining information from the patients and many times are not sure of the kind of information they need. During the acute phase of illness the student can easily identify the information she needs to know, but in this phase she has few leads. She is confused about what to do and she needs guidance to develop ideas. Because of these complexities, the major part of the students' experience is devoted to caring for this latter group of patients. The rotation is designed so that one-third of the time is spent with the acutely-ill person and two-thirds with patients who have been in the sanatorium for some time.

Throughout the experience, discussions are held daily with the Director of Nursing about the care of the students' patients. The focus of these conferences is to pool information about the patient, his family, home, and occupational status. For the most part the Director of Nursing is able to provide relevant information because of the many roles she has assumed in relation to her position. Thus she acts as a model for the students in terms of knowing the patient as an individual and in using this information to help him. At the same time the physician, occupational therapist or psychiatrist may be asked to join the discussion. In these sessions students can see the nurse acting as the motivator and co-ordinator of activities beneficial to the patient. The sessions allow the students to talk over their successes, to seek help with their difficulties, and to share their frustrations. They learn to adapt their nursing intervention so that it is relevant to the particular phase of the patient's illness.

The sanatorium is located in the Laurentians approximately 60 miles from the city. The location of the institution separates the student physically from her family, friends and normal social life. When she leaves for the ten-day consecutive experience she does not view this as a long time period and so does not make any plans to bridge the separation. Thus, unexpectedly and not by choice the student finds herself in a situation not unlike that of the patient in that she experiences some of the isolation he is feeling. Due to the concentration of the learning experience, the student has little opportunity to pursue activities other than those centered around life at the sanatorium. Her daily activities closely resemble those of the patient even to the adoption of some of the same routines to pass the time of day. Frequently the student spends a large portion of her time with a patient and gradually becomes absorbed in his life. This helps her appreciate the timelessness and the monotony he feels. The very proximity of the student residence to that of the patients' contributes to her awareness of the values, norms and customs of the sanatorium community. This modified "total immersion" adds to the student's understanding of the problems facing the patient both while in the sanatorium and when the time comes for him to return to his former community.

Through this experience the students are able to tie together many different kinds of knowledge they have acquired during the year. They have the opportunity to spend time with the patients and to think through and test out their ideas so that their knowledge and ways of nursing become more relevant to the needs of the patient.

In this paper I have attempted to outline those aspects of nursing in chronic illness which student nurses need to learn and to show the structure that is emerging for our students to accomplish this purpose. Although the paper deals mainly with the care of patients who have tuberculosis, I feel that many aspects of it can be generalized to patients with other chronic illnesses.

FOOTNOTES

1. Moogk, H. "Learning to Nurse Patients in Labour," *Nursing Papers*. Montreal: School for Graduate Nurses, McGill University. (April, 1969), p. 6.

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