New Beginnings in Chronic Disabling Illness

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Chronic disabling illness may present the opportunity for a new beginning in the life experience of the patient and involved family members. Two cases illustrating the phenomenon of "new beginnings" in chronic disabling illness are presented. Family physicians need to be alert to the constructive change in life adaptation that may become possible when old patterns are no longer possible and new adaptational patterns emerge.

The drastic personal and social consequences of illness are well-known. Biologic dysfunction impairs the ability of an ill person to fulfill his social role. The degree and duration of such disruption depends upon length of illness and the permanence of disabling effects of the biologic and psychologic changes. Changes in the patient affect other members of the family necessitating the establishment of a new family homeostasis. The destructive effects of disease may encompass all areas of human involvement within the family. Parent-child and spouse relationships, economic status, and behavior patterns may all be altered in the wake of serious illness, particularly illness which leads to a disabled state.

Optimum treatment of a patient requires not only sound scientific medical management, but also an awareness of the consequences of illness on the lives of patients and their families. Such knowledge leads the family physician to undertake supportive, rehabilitative measures while remaining alert to the new needs of other family members.

The deleterious effects of illness are well-known to physicians. Less readily recognized are the constructive changes which an illness may lead to in a patient as well as in the family. A serious illness may act as a catalyst to new attitudes, life styles, value systems, and relationships. Such new directions can become a new beginning for the patient as well as other family members. These new beginnings will often lead to greater fulfillment and appreciation of life than the patient had ever known before.

Case Reports

Recent observations by the authors have substantiated this observation. Weekly conferences of the Department of Family Practice at the Medical College of Wisconsin focus on the experiences of patients with chronic illness. Two cases have been selected to illustrate the "new beginnings" phenomenon in chronic disabling illness.

The first patient is a 51-year-old woman whose past medical history includes a stab wound to her chest in 1952 with left hemothorax and good recovery. Subsequently she made occasional visits to the hospital outpatient clinic for episodes of chest pain and bronchitis. She also had one blackout spell. In 1965, she had two episodes of epistaxis, one requiring blood transfusion. During this admission, she suffered from chills and shaking probably related to alcohol withdrawal. She was also known to be a heavy smoker, one pack per day for about 15 years. Notable in her family history was the fact that her mother died in her early fifties of cancer of the larynx following treatment by laryngectomy. Prior to 1970 the patient lived with her husband and had a circle of friends with whom she spent a good part of her life at "parties" focused on gambling and drinking.

In early 1970, following arrest for gambling, there was a complete breakup of the group. The patient was separated from her husband and lost contact with the other members of the group. According to the patient, most of them are now either dead or in jail. At this time, she had already noticed a persistent hoarseness and, after an episode of hemoptysis, she decided to consult an otolaryngologist in April, 1970. She maintains that in spite of symptoms and family history, she did not believe she had cancer at this time. Nevertheless, she was found to have cancer of the arytenoids and false cords with a single enlarged lymph node on either side of the neck. A tracheostomy was done and radical surgery scheduled. But the patient refused surgery and was too agitated to be

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given radiation therapy. The radiation therapist felt she was psychotic and a psychiatric consultant noted her state of considerable emotional turmoil. She refused all therapy and kept pulling out her tracheostomy tube. However, after discussing the matter with her daughter and a social worker, she eventually had a change of heart and underwent laryngectomy and right radical neck dissection with hemithyroidectomy on May 12, 1970. On July 16, 1970, she had radical neck dissection on the left side. Nodes from the left side contained tumor cells. Fifteen nodes from her first surgery were all negative.

Recovery from surgery went well, although the patient needed stomoplasty for stenosis in September, 1970. In the meantime she had been started in speech therapy where she made little progress and had a very poor attendance record. "I didn't want to learn," she has said. Therapy was discontinued for about six months until early 1971 when she expressed a desire for further therapy. She says she no longer felt she was going to die from her disease. Finally, after about one year, she achieved esophageal speech.

Following surgery the patient lived with a married daughter, son-in-law and grandchildren. Later, with much struggle, she moved out and now lives alone. This is the first time in her life she has been able to live alone and care for herself independently.

Four years after surgery there has been no recurrence of the neoplasm. Her health is good, weight is stable. In an interview she commented on her initial adaptation problems and said there were three main problems in adjustment. First, the realization that the stoma was permanent. Second, the reaction of people upon seeing her stoma (she recounted an incident in which a fellow passenger on the bus fainted after initiating a conversation with her). Third, the adjustment to living alone. The processes of adaptation have taken time and although she admits to "missing my beautiful voice" there is no indication that she now uses any alcohol or tobacco, or that she gets overly depressed. She is generally cheerful and has become supportive and helpful to people involved in her life.

The second patient is a 56-year-old woman, married for 40 years. Her husband is 23 years older than she. They have no children. Over 20 years ago she was told she had high blood pressure. She was given pills and informed about the complications of untreated hypertension such as strokes and heart attack. But she took her medicine very sporadically. In 1968, she had several brief admissions to a psychiatric hospital. The first time she was admitted on a police detention for "seeing things." Later it was learned that, after a drinking bout, she had fabricated stories about affairs with other men. This made her husband threaten to kill her and she had locked herself in the bathroom prior to hospitalization. She calmed down in a few days and was discharged with a diagnosis of anxiety reaction. Shortly after this episode she was admitted in a state of delusional agitation. She had called the police claiming to have heard gunshots and she maintained that someone was trying to kill her. Again, she improved in a few days. At this time her husband characterized her as a "problem drinker" of some four to five years duration. She had high blood pressure and was referred for treatment. On August 26, 1968, she was again admitted for "paranoid state, involutional," with fears of neighbors trying to kill her. After this admission she and her husband moved to a different neighborhood and she seemed to improve. The patient was not hospitalized again until 1971 when she had a stroke with right-sided hemiplegia and aphasic symptoms. She spent four months in the hospital including time of rehabilitation. She improved but had residuals of paresis of the right arm and leg. She recovered her speech almost completely and learned to ambulate with a brace and a cane. She is able to perform restricted household tasks such as making beds, dusting, cooking and dishwashing. Her now 78-year-old husband does all the heavier housework such as laundry and vacuuming. The patient no longer has an alcohol problem. She takes antihypertensive medication regularly and her blood pressures now range between 150/96 and 130/90. She had a problem of considerable weight gain but controlled it by dieting faithfully for a year. She has had no mental symptoms since the stroke and enjoys her life even with its limitations. The marital relationship is now a cooperative one with each partner sharing tasks within his or her capability. The patient's disability has seemingly created a more stable homeostasis within the marriage.

Discussion

Since family physicians are deeply involved in supportive and rehabilitative medicine, awareness of the phenomena described above is particularly relevant to them. Care of the chronically ill is a formidable task and not the least of the problems are physician attitudes. Studies of medical students reveal early attitudinal problems about chronically ill patients.[1] Physicians all too commonly feel that all is lost when a patient cannot be cured. Such attitudes lead to decreased involvement with such patients. For these reasons, it would appear that physician recognition of the possibility of a constructive change through illness would prove important in the care of chronically ill patients. The ability to perceive the possibilities for beneficial change in a patient's life (as well as in family members) as a result of a chronic disabling illness would be a boost to physician morale. The presence or absence of physical illness is not the ultimate parameter for assessing life. A better human adaptation may indeed become possible in the context of human illness. Armed with such awareness and experiences, the family physician can himself serve as a catalyst for the process of new beginnings in patients and their families.

Reference

1. Ort RS, Ford AB, Liske RE, Pattishall EG Jr. Expectation and experience in the reactions of medical students to patients with chronic illness. *J Med Educ 40(2)*:840-849, 1965.