Effects of Chronic Illness on the Family

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Chronic illness is perhaps the most common type of illness encountered by the physician in our society. The clinical management of chronic illness includes a consideration for the social, cultural, and psychological situation of the patient and his family. This paper examines some of the common effects of chronic illness on the family and indicates how the family physician can assist families in adjusting to chronic illness, which will facilitate its clinical management.

Our personal experiences tell us that illness is a potent agent of change. Chronic illness especially disrupts the usual ways in which family members behave toward one another and then hampers their ability to overcome the effects of this disruption. The effects of chronic illness on families are more often disintegrative than integrative; indeed, they change the attitudes and behavior of both sick and well family members, as individuals and as members of a family unit. Tasks and responsibilities must often be reassigned and this creates a period of disequilibrium. The duration and outcome of family disequilibrium is influenced by the clinical manifestations and management of the illness as well as how well the family adapts to the changes created by the illness.

The purpose of this paper is to examine some common effects of chronic illness on the family and to indicate how the family physician can assist families in adjusting to chronic illness.

Chronic Illness Creates Role Change

Short-term changes in the role structure and task allocation in families as a result of illness are similar to the permanent or long-term changes caused by loss of one parent.[1] When duties and responsibilities are taken away from one family member and assumed by another, often one will feel a sense of loss and the other feels burdened. Role change and task reallocation is perhaps easier to accept in short-term illness. In chronic illness, the ill person and other family members assume or hope at first that role change will be temporary. Indeed, if the clinical course of the illness stabilizes, or there is improvement, the ill person may regain some of his former family functions. If the clinical course of the illness declines, however, and duties and responsibilities must be removed from the ill person rather abruptly, he or she may feel a real sense of personal loss. The patient, especially one with a long-term illness, is sensitive to his dependence upon others and if his former duties and responsibilities within the family are completely removed, he will feel unneeded. Roles must be changed and reallocated in ways which minimize a sense of personal loss and prevent the ill person's social and psychological withdrawal from the family. We are familiar both with chronically ill persons who "gave up" living and became resigned to their illnesses and with ill persons who attempted to overcome the effects of their illness with determination, hope, and a "will to live." The latter group have usually retained a role within the family and feel wanted and needed.

Thus, it is important that the physician realistically convey to the family what the ill person can and cannot do with respect to duties and responsibilities. Discussions with the physician, the ill person, and the family members should be held periodically as the course of the illness changes. The ill person should be a part of these discussions so that his expectations can be geared to the clinical progress of his illness and possible paranoia about "what they know that I don't know about my illness" can be avoided.

The See-Saw Effect of Illness

The chronic illness of one family member may create new, or revive former, symptoms in other family members, especially as roles are changed. The interactive effects of illness on marital pairs was studied by Klein and his associates in chronically ill outpatients and their spouses.[2] They found that the development of physical illness by one marital partner

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was accompanied by his failure in his role, which led to tension and physical symptoms in both partners. Klein observed that spouses reported new or increased symptoms during the illness of their partners. In addition, there was increased role tension between patients and their spouses and a reduction in work activity of both partners. Some spouses showed more symptoms than their ill partners. This latter finding led Klein to ask, "how does one family member become defined as 'the patient'?" The researchers speculated that some spouses are symptomatic before the patient is treated and may be waiting in the wings to become patients themselves. Thus, alternating illness between partners may be related to changes in roles rather than to the development of a new illness.

Vincent has suggested that there may be "familsomatic" ailments that accidentally or purposefully, real or imagined, are developed to avoid certain tasks, since the illness of one spouse increases the tasks of the other spouse.[3] Indeed, the development of symptoms is one way of sharing attention and concern, especially if the illness of a family member has diverted attention away from the "well" members of the family.

It is possible for a person disabled by illness to achieve secondary gains for himself as well as to behave in a manner that will increase gains for others. It has been found, for example, that when some husbands lose their capacity to earn a livelihood they attempt to compensate for this inadequacy by becoming more considerate of their wives, helping around the house, and changing their usual role behaviors in the family.[4] It may be that the value the person places on his various life activities helps to determine how disability in one role affects his performance in others. If the disability occurs in a role which is only one of several which are important and satisfying to the person, disability will be less destructive to his identity than if there are no role options.

In the clinical management of chronic illness, it is important to recognize that a sick member may become sicker in response to role changes in the family and "well" members may become "sick" to call attention to themselves or to the need to reallocate tasks, especially if they feel overshadowed or overburdened by the ill family member.

Predisposition to Certain Roles and Illnesses

There is some evidence to indicate that illness does not just "happen" to people and that individuals and families do not just "react" to the occurrence of illness. Lewis has observed family patterns of illness or a tendency in some families for illnesses to cluster. He raises the question, "Is there a way of being a family which influences the vulnerability of family members to all disease processes?"[5]

A study conducted at the University of Michigan found substantial social effects of rheumatoid arthritis that are perpetuated between parental and conjugal families.[6] Women with rheumatoid arthritis make marriages which resemble those of their parents; there is a high degree of status stress (great discrepancies between their own and their husband's status on several factors measuring status), and they are more likely to be married to men whose status variables are incongruent. Women with rheumatoid arthritis feel and express a good deal of anger and aggression toward their husbands as well, which is reciprocated by the husband. This mutually directed anger-aggression was shown to relate significantly to the appearance of peptic ulcer in the husband. Men with rheumatoid arthritis were found to be low in feelings of anger and aggression and their rather benign attitude was reflected in the low level of marital hostility in marriages to healthy women. Thus, there is some indication that roles are carried from parental to conjugal families and that the interaction between certain types of roles over time may create a setting in which certain chronic illnesses may occur. For example, Sampson and his colleagues found that a family member is likely to become defined as a mental patient when he tries to break out of a chronic pattern of either intense dependency or of disinvolvement with other family members.[7] In essence, the person is labeled a mental patient when he tries to change his longstanding role in the family and disrupts the family organization.

It is important for the physician to determine the role that the ill person occupied both in his parental and conjugal families, as this information will tell a great deal about the expectations that family members hold of the ill person with respect to his future role and responsibilities. For example, there is evidence that a family member who is mentally ill is less likely to be hospitalized or rehospitalized if living with his parents.[8] In the setting of the parental family, the mother especially is more likely to tolerate deviant behavior and there are few, if any, pressures to be independent. Therefore, role shifts among one or more family members can signal the onset of illness. Role shifts among "well" family members may also be necessary to fill voids created by a sick member. Although sources outside of the family are often available and helpful in filling voids, neighbors and friends supplement, rather than compensate for, family sources of aid. Hence, members must act to restore equilibrium within the family; sources outside the family can assist in this endeavor, but they alone cannot hold a family together.[9]

Family Breakdown – Failure to Adapt

The rate of breakdown in families with severe chronic disease is high. It has been shown that the combined effects of poor health and unfavorable family situations are cumulative over time.[10] Diabetes mellitus, hemophilia, and epilepsy are examples of chronic illnesses with high rates of family breakdown. Family breakdown in these instances often results because family members would not or could not change roles and reallocate tasks.

The presence of a diabetic child is associated with lower marital integration and greater conflict among parents. Although a new equilibrium can be established in the family, it is often less stable and integrative than before the chronic illness.[11] The families of diabetic children show a variety of psychological structures.[12] Since diabetes enforces a certain way of life, the child and his family react according to preexisting yet unspecific patterns. Diabetes seems to reinforce existing patterns. Childhood diabetes presents numerous difficulties because of the susceptibility to other diseases, changing requirements of growth, unpredictable outbursts of physical energy, and emotional disturbances. The effects of the disease continue throughout adulthood, influencing the diabetic person's educational, marital, and occupational plans. Thus, as the diabetic person grows older, problems expand into other systems outside his immediate family.

The presence of a hemophiliac son can draw parents together. In the majority of families, however, hemophilia contributes to the withdrawal of the husband from family relationships and to the breakup of the marriage.[13] Hemophilia limits family mobility, creates financial strain, generates feelings of guilt and resentment among the parents, and often strains the relationships between healthy sibs and the hemophiliac child.

The idea that epilepsy is a shameful disease is often foremost in the minds of the parents of an epileptic child. Many parents feel that epilepsy has a hopeless prognosis, especially if a cause cannot be discovered for their child's convulsions. Parents may become protective of the child with respect to emotional excitement and physical activity. Young children sense any type of restraint and soon learn that others, even family members, do not see them as normal. The actions of others help to mold the epileptic's self-image which, in turn, influences his educational, marital, and occupational plans.[14]

Chronic disease in a child or adolescent is perhaps more difficult for the physician to manage clinically for several reasons. (1) Parents often protect the chronically ill child or adolescent from learning adult roles and responsibilities. (2) The chronically ill child or adolescent may learn to use his illness as with, for example, control over diet and insulin in diabetes to "get his way," learning, possibly, that manipulation of others is a successful way to solve problems of living. (3) The chronically ill child or adolescent is permitted by society to have more freedom in the expression of feelings and behavior regarding his illness than adults. So, when he becomes an adult, he may have to learn new and more socially acceptable ways of expression and behavior. (4) The chronically ill child or adolescent usually lives with one or both of his parents or relatives who impose their perception of the type of life style or routine that the ill person should follow. Therefore, the young chronically ill person may not be able to adjust to his illness as he wants to. (5) The chronically ill child may be the "lightning rod" for marital and family problems, so his and his family's adjustment to the illness is further complicated.

These issues, which must be discussed with the parents, present problems for the physician in the clinical management of chronic illness. Parents often think they are being thoughtful and helpful in removing tasks and responsibilities from a sick child completely, especially from a child with a chronic illness. Indeed, such action may foster feelings of hopelessness and helplessness and work against good clinical management of the illness. Chronically ill persons, irrespective of age, must retain their integrity as human beings and be given the opportunity to participate in their families and society as their social and clinical circumstances permit.

Role Expectations and Adjustment to Chronic Illness

What others expect of the ill person will influence how he adjusts to his illness as well as the degree of success in the clinical management of the illness.

Davis studied the social-psychological impact of spinal paralytic poliomyelitis on the families of 14 children, ages four to twelve.[15] He observed that when the child made significant strides in his physical capacities, there was an aura of achievement in the family and often unrealistic parental expectations regarding recovery. In those families in which the child showed little or no functional improvement, family members hoped for a spontaneous cure, and rehabilitation gains were neglected or only half-heartedly pursued. As might be expected, the adjustment period was more difficult, prolonged and pervasive in families where the child remained handicapped. However, many of these families appeared to be coping also with other longstanding problems that tended to merge with those created by the chronic illness. Thus, it is not surprising that the families leaning toward dissociation from the chronic illness tended to isolate themselves from others, whereas families tending toward normalization denied the social significance of the handicap rather than the handicap itself. So, the degree of success in the rehabilitation of youthful polio victims was intimately tied to the social climate and outlook on life of their families.

Ezra, in a follow-up study of 50 men who had heart attacks and their families, found interesting discrepancies between the interpretations of family difficulties by husbands and wives.[16] The problems most frequently mentioned in interviews with the husbands were: (1) financial problems, (2) depression, (3) curtailment of activities, and (4) fear of recurrent attack. The wives, however, responded that stress and tension as a result of their husbands' illness, financial problems, and the adjustment of their husbands were more crucial concerns. The wives of these disabled men believed that their husbands had more serious problems of adjustment than they would admit, and a high percentage of the wives believed that the family could have benefited from counseling. Respondents were also asked how they felt about the way responsibilities were handled in the home as compared to the way they were handled before the disability. A complex relationship between financial stress and changes in role relationships was found. The greater the financial difficulty resulting from the disability, the more negative were family reactions to the disability and the changes it produced.

Landsman has observed that patients with chronic renal failure all share in a desperate effort to determine for themselves a realistic set of expectations and goals.[17] After the initial impact of illness dissipates they tend to find themselves adrift somewhere between the worlds of the sick and the well. Marginal men, in effect. According to societal expectations the patient with renal disease is not sick, for unless he is severely impaired he is expected to pick up where he left off at the time of hospitalization and resume his former obligations. The marginality between what society defines as healthy and the fact that every aspect of life is altered by his dependence on dialysis is responsible for the renal disease patient's inner struggle to arrive at an appropriate self-image.

The physician also has his own expectations of the ill person regarding his motivation, his compliance with clinical regimen, and his cooperation in controlling the illness. The ill person must sometimes balance the expectations of family members with those of his physician. Thus, it is important that the physician, the family, and the patient discuss expectations jointly so all will arrive at realistic expectations regarding adjustment.

How Families Cope with Chronic Illness

Families with greater family strain seem to have more illness than families with less strain. Yet, badly functioning families are not less ready to cope or to seek help. How families cope with chronic illness and whether or not they seek help to adjust is tied to how they cope with other problems of living. If the family has ways of coping that work for them, they are less likely to see the need for help. To others outside the family, these coping patterns may be seen as maladaptive or as conflicting with the effective clinical management of the illness. Families have been found to feel less threatened by illness for which they have well-established coping rituals than for other types of life problems for which there are no rituals.[1] Many individuals and families feel comfortable in coping with acute illness. But chronic illness is insidious in onset, difficult to treat and contain, and its clinical course is often unpredictable. Therefore, chronic illness may not fit the ways a family has established for coping with acute illness. Any suggestion that a family's way of coping with chronic illness is ineffective would create much anxiety and imply that the family does not cope effectively with problems of living. So it is important that the physician ascertain the family's way of coping with life problems previous to the diagnosis of the chronic illness before he makes judgments about their effectiveness in coping with the chronic illness.

Since chronic illness is progressive in onset the family may have been told earlier of the gradually debilitating effects of an illness diagnosed in a family member, but they may have chosen to deny or ignore this until the effects were undeniable. In addition to denial there is a variety of feelings such as guilt, anxiety, shame, embarrassment, depression, resentment, rejection, alienation, self-blame, and bitterness which are a part of a family's armamentarium in coping with chronic illness. The family must be assisted in resolving the emotional antecedents and sequelae of the illness before it will be able to satisfy the emotional needs of its members. Unless a family's emotional baseline is reestablished, role change and task reallocation will be emotionally painful, if not impossible, to carry out. This reestablishment is necessary for minimization of the negative effects of poor family dynamics on clinical management of the illness.

Family members have been found to go through stages associated with cancer similar to those the patient experiences. There is shock and anger at the diagnosis, guilt for missed past appointments, and a period of anticipatory grief and hope, at first for curative drugs and later for one more remission.[18] For families coping with cardiovascular disease, a key factor is that the family members be given information routinely along with the patient. How well the family is organized can be a crucial factor in how well the patient follows a therapeutic regimen. But a crucial way for families to cope with cardiac illness is to work together and communicate freely, especially during the period of convalescence. What heart patients need most is emotional support and guidance towards a realistic style of work and home life.[19]

Implications for Physicians

The doctor-patient and doctor-family relationships are critical ones for chronically ill patients. For some chronic illnesses, such as cancer, there is little patients can do to alter the disease once treatment has begun. For other chronic illnesses such as diabetes, patients can control their disease through diet and insulin. Whatever the degree of individual control over the illness, the physician is seen as a symbol of hope by chronically ill persons. The key to coping with chronic illness is having and maintaining hope. Although the patient and his family have to cope somehow with changes in life style and roles, few people can make these adjustments without periods of discouragement, anxiety, and resentment. The family physician is in a key position to enhance the changes for successful clinical and psychosocial adjustment to chronic illness by using his knowledge of the family and its dynamics to create strong family support for the ill person. Physicians, like their patients, are not immune to feelings of discouragement in treating chronic disease. Many physicians prefer not to tell their patients and families the truth about the clinical course of a chronic illness. Direct two-way communication between physician and the family is essential because it builds confidence and rapport. This is often the most effective treatment available for chronic illness.

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