Physical Illness: The Family and the Physician

MARC H. HOLLENDER

Department of Psychiatry, University of Pennsylvania
School of Medicine, Philadelphia 19104

The traditional approach of the physician to members of the patient’s family has been to send them off to boil water and find clean sheets. Although I am not prepared to summarily dismiss a tried and true method, I would hope that with our new therapeutic skills and hard-won psychological sophistication, we, as physicians, are now able to work with the family in a more meaningful and constructive manner.

As the understanding of disease processes and psychological reactions has enlarged, so has the physician’s task. Initially he confined his attention to a symptom and its effect on the patient, which, has sometimes been recommended, to involvement of the relatives and the patient in family therapy, which currently is popular. Obviously I must circumscribe the field if I am to stay within my allotted time. I will do so by confining my remarks to the role the physician should usually take in working with families of those patients who have illnesses which are serious and disabling but not necessarily fatal.

Stages of Reaction

According to Garrard and Richmond (1963), the reaction of parents of chronically ill or handicapped children can be divided into three stages: 1) the stage of disorganization; 2) the stage of reintegration; and 3) the stage of mature adaptation. These divisions, which are helpful to the physician in understanding and dealing with parents, are equally applicable to the situation in which the seriously ill patient is an adult, and the family members, instead of being parents, are the spouse and grown children. Let us consider each stage of the family member’s reaction in detail.

Disorganization

Disorganization in its extreme form occurs in response to a sudden and overwhelming catastrophe. Less severe forms usually occur in response to events that merely overtax a person’s coping mechanisms. I would hasten to point out that it is impossible to predict how one will react to the illness of a close relative on the basis of his reactions to other stresses. Each person has highly specific vulnerabilities, so that, for example, a person may weather military combat well but crumble when confronted by the illness of a close relative. The physician who complains about the miserable or horrible relatives of his patient should try to bear in mind that, under almost any circumstance other than illness, he might find them affable and likeable. The threat posed by illness and the inability to mobilize effective coping mechanisms immediately may elicit the most difficult behavior in the family members.

In the face of disorganization, how does the family handle the situation? The first coping mechanism is usually denial. Denial helps avert disruptive disorganization and sustains the relatives until the passage of time allows for the development of an increased capacity to deal with harsh facts. As Garrard and Richmond (1963) pointed out, however, complete denial in the face of obvious disability is a poor prognostic sign, because it suggests that sustained difficulty will be experienced in perceiving and dealing with reality.

Another coping mechanism, projection, is especially well-suited for handling guilt and, thereby, limiting the degree of disorganization. It represents an effort to push off feelings of responsibility, feelings that are intolerable. A family member can blame the physician, or he can blame another relative. If the physician’s care is held responsible, his capacity for understanding and forbearance may be overtaxed, and, unfortunately, this may cause him to retaliate in kind. If another relative is blamed, a tenuous relationship may be seriously disrupted at the very time it might otherwise serve a mutually supportive function.

Still another coping mechanism, regression, may have even more
crippling consequences than the first two. In the following example, regression was the response to a disabling illness, the relative's psychodynamics and the physician's unfortunate approach to the total situation.

Mrs. A., a 70-year-old woman, had been in good health until her 75-year-old husband had a stroke which left him an invalid. After the initial critical period of Mr. A's illness, she developed a severe diarrhea accompanied by marked abdominal distress. She also had many anxiety symptoms. She could eat nothing but baby foods, and she drank large quantities of milk. She dropped all of her activities, constantly talked of her symptoms, and demanded much attention. When the physician told her that her husband would never be any better, that she would have to adjust to him as he was, and that, if necessary, she would have to treat him like a helpless baby, all her complaints became more marked. Not only was she under more tension than before, but her relationship with her husband became so disturbed that she made life extremely difficult for him.

In this instance the husband's stroke and the necessity for treating him like a helpless baby played directly into an unresolved childhood conflict. Mrs. A. had been the oldest of ten children, and, long before her own needs had been met, she had been called on to take care of younger siblings. Her reaction to her husband's situation was to regress to a very dependent state (i.e., to that of a helpless baby). At the same time her marked jealousy and resentment of her husband created considerable guilt. When she was relieved of the pressure to be the strong one and was provided with support by the physician, her emotional balance was reestablished, and with it a more helpful attitude toward her husband (Hollender, 1958).

I have mentioned three coping mechanisms. They are among those most often used, but there are others that also help to soften the blow and limit the extent of disorganization. They include intellectualization and isolation; both serve to separate the effect from the event. Using these mechanisms, one can deal with the situation so dispassionately that the sick person seems to be as far removed as the newspaper account of a man starving in India. Avoidance is still another mechanism. The relative may stay away entirely, or, if present, may avoid major considerations and focus his attention on minutiae—a complaint about a minor detail of hospital care or the patient's failure to have a bowel movement. Thus far I have spoken of the means used to limit disorganization or to cope with the forces responsible for it. At this point, let me comment about those feelings which promote disorganization—principally, anxiety and guilt.

Anxiety immobilizes some persons but has the reverse effect on others. The latter are propelled into ill-considered and, perhaps, ill-advised activity. The need to do something—action for action's sake—results in activity that serves as little purpose as a boxer's punches when he departs from his fight plan and flails the air. The agitated and desperate relative may exert pressure on the physician for premature treatment, or he may take the patient from physician to physician in quest of a magical remedy. Perhaps the proverbial instruction to "go boil water," which I mentioned at the beginning of this talk, is the physician's intuitive effort to channel anxiety into harmless activity.

Guilt may produce as disruptive an effect as anxiety. In severe form it can be characterized as guilt-seeking. Mark Twain was a guilt-seeker. As Barrett (1955) noted, Mark Twain felt responsible for the welfare of his family and was prone to be self-accusatory. "At the time of his younger brother's death his assumption of guilt became grotesque. Henry died as a result of being severely burned and perhaps internally injured in a steamboat explosion, but the older brother went to great lengths to find reasons . . . for what had happened. He blamed himself for Henry's presence aboard the boat, for not being himself aboard to help and protect him (this required the presumption that he, himself, would not have been injured) and, finally, for what he feared might have been an overdose of morphine which he urged a young doctor to give for the relief of pain shortly before Henry's death."

Let us now consider how the physician can be helpful to the family during the stage of disorganization. First, he should be aware of the feelings the relatives are experiencing and recognize that many reactions are reasonably appropriate—not merely annoyances specifically designed to complicate his task of treating the patient. The appropriate reactions require understanding and support; the inappropriate ones require more definitive measures.

In considering the physician's role as a supplier of information, it should be borne in mind that nothing is more difficult to handle than uncertainty. The family member who has little knowledge of the situation, like the small boy in the dark, can imagine eventualities worse than any known to medical science. Physicians, guided by their own value system of truthfulness or helpfulness, will impart more or less information. I personally favor the guideline of helpfulness. In keeping with this approach, the family should be given pertinent information but need not be acquainted with every possible eventuality. I agree with the well-known surgeon (Mayo, 1968), who said, "I have no great admiration for truthfulness that isn't also kind." Encouragement and helpfulness should be offered whenever reasonably consistent with the facts.

As previously mentioned, some
degree of denial, short of complete denial, should be expected during the early period. It should be respected. Only gradually should an effort be made to reduce it. Usually without combating it, the physician will note that it diminishes in extent as the family member comes to grips with the situation facing him.

The response to projection, especially when the physician's treatment is the object, is a more difficult problem. The more insecure the physician himself feels about his treatment, the more easily he is challenged by the family member's projection. Even under the most favorable circumstances, however, it will tax his tolerance and forbearance. To do battle at this juncture serves no useful purpose. Instead, it usually causes the family member to tighten his hold on his accusations. The physician's best approach is to supply information which lessens guilt and removes the need for projection.

Reintegration

The process of reintegration may begin within a period of minutes, hours, or days, or it may be delayed for weeks. As previously mentioned, the physician can foster it by recognizing that some forms of disorganization are transitory as well as expected. Conversely, he can impede it by not only failing to supply essential information and much needed support, but also by reacting to manifestations of disorganization with impatience, annoyance and anger.

Activity on the part of a family member, especially if it is constructive, promotes reintegration. It interrupts the downward spiral produced by feelings of helplessness and passivity. In instances where the patient is too ill or disabled to participate in decision making, a relative must assume the responsibility. Similarly, the parents of a chronically ill or disabled child should be called on to participate in his care.

During this stage denial, projection, intellectualization and isolation—essentially emergency measures that have been quickly mobilized to limit or contain the extent of the disorganization—tend to recede or disappear. They are replaced by efforts to face the situation as it is and to do whatever is helpful under the circumstances.

Some relatives regain their balance by relying heavily on the support they receive from the physician as an authority until their own strengths can be mobilized or developed. Young parents of a chronically ill or handicapped child may be especially needful of such support (Garrard and Richmond, 1963).

The process of reintegration is illustrated by the following case notes. A 52-year-old married woman, the mother of two young adult daughters, had undergone a left ovarian cystectomy six years earlier for what proved to be a pseudomucinous cystadenoma free of malignancy. Four years later (or two years before the present illness) a total hysterectomy and a right salpingo-oophorectomy were performed for an ovarian cyst. The cyst was diagnosed as benign. One month before the present admission, the patient began to experience mild indigestion and constipation and lost 15 pounds in a period of weeks. Her family physician felt a moveable mass in her left lower quadrant and referred her to a surgeon for treatment. On examination the surgeon confirmed the family physician's finding and also thought he detected fluid in the peritoneal cavity. These clinical findings suggested an intra-abdominal malignancy, but since the diagnosis was uncertain, the surgeon merely told the husband that an operation was indicated and emphasized his concern that he might find something "bad."

At operation, multiple intra-abdominal metastases and two or three quarts of fluid were found. The primary source was believed to be one of the ovarian cysts previously diagnosed as benign. When the findings at operation were described and their implications explained to the husband and two daughters, they reacted as though they were completely unprepared for this eventuality in spite of the warning they had received beforehand. Their next reaction was to try to place blame—on the previous surgeons, the present one and/or themselves. They asked who would discuss the situation with the patient, and they were visibly relieved when the surgeon said that he would. At this meeting, they were informed that Cytoxan would be given for palliation.

Three days later, when the surgeon again spoke to the husband, it was as though the information the husband had received—the diagnosis, the incurability of the illness and the proposed use of palliation—was all brand new. By the time of the next meeting five days later, however, some reintegration had taken place. The husband was beginning to accept the diagnosis of malignancy and was hopeful that Cytoxan would afford effective palliation. He even discussed purchasing a wig to cover the hair loss that the treatment would cause. Reintegration had taken place in a matter of days, and it was evident that an adjustment to the harsh reality would soon follow.

Adjustment

Garrard and Richmond (1963) qualified adjustment with the word "mature." I choose to delete the qualification, because for practical purposes I am speaking of the reestablishment of a state similar to that which existed before the crisis. "Mature" introduces a new dimension and one that is sometimes difficult to define.

To indicate more specifically what is meant by adjustment, I will discuss the case of the parents of a chronically ill or disabled child (Garrard and Richmond,
During the first two stages, guilt feelings may have been evident through conscious thoughts concerning errors of omission or commission. Self-sacrificial devotion and overprotection are also evidence of unresolved guilt. Self-criticism and overindulgent behavior dissipate when the stage of adjustment is reached.

Since the parents of chronically ill or handicapped children frequently are frustrated and angered by their fate, they may hold the sick child responsible for their burden and discomfort. Because of their anger, they struggle with guilt. The result is inconsistency in the handling of their child—vacillation between anger and guilt. Characteristically, they shift from harshness to a compensatory overindulgence. As these parents reestablish their adjustment, the inconsistent behavior diminishes and, finally, largely disappears (Garrard and Richmond, 1963).

Some persons, especially those with well-developed obsessive character traits, prepare in advance for possible eventualities. Since they are not caught by surprise and are ready with what the Army calls "contingency plans," they largely circumvent the stages of disorganization and reintegration and make an immediate adjustment to illness in the family. A 34-year-old woman had the habit of asking herself, "What would I do if . . . if my husband became ill? If my children were lost? If my car went out of control?" She explained that, for other people, thinking of a crisis would have a bad effect, but for her, it had a good effect; it reduced her tension. By thinking ahead she felt ready to meet almost any emergency. She placed great value on being self-reliant, and she traced this attitude back to the childhood fear that her parents would leave her and not return. Her outlook was: You cannot be sure that another person will be there when you need help; you must plan ahead and be ready to handle your own problems. When her husband did become ill, she met the challenge without signs of even transitory disorganization.

Evidence should be sought for failures in adjustment. The general question, "How are you doing?" is poorly designed to obtain this information. Too often it sounds like the social convention of asking at a cocktail party, "How are you?" and brings forth an equally routine or thoughtless answer. It would be more meaningful and productive, for example, to ask the woman who comes to the office some weeks following her hysterectomy about her sexual relations. If such a question brings forth tears and other evidence of unhappiness, it may be essential to talk to her husband. At this juncture the husband usually does not need an intellectual discussion or a sermon. A bit of direct prodding is more to the point. He should be told, "Your wife is as good sexually as she ever was," and he should be enjoined to let her know he finds her attractive. Such statements are icebreakers and foster the husband's adjustment as well as that of his wife (J. R. Wolff, personal communication).

**Summary**

The modern American family has been described as a precariously balanced, emotionally highly charged system, lacking in ready shock absorbers to handle, within itself, serious illness (Parsons and Fox, 1952).

When confronted by the specific stress of a close relative's illness, the family members' reactions may be schematically divided into three stages: 1) disorganization; 2) reintegration; and 3) adjustment. Either disorganization can be intensified or adjustment can be fostered, depending on the physician's understanding of the feelings the family members experience and his willingness and ability to be helpful. The family members’ responses, in