1979 Psychiatry in General Medical Practice

Chapter 5

Reactions to Physical Illness and Hospitalization

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EDITORS' INTRODUCTION

What is it like to be a successful businessman who is secure as a person, competent as an executive, is constantly being looked to for advice and leadership, and then suddenly to find oneself a patient in a coronary care unit? What is it like to feel helpless and totally dependent upon others?

The author delineates the cardinal features of illness. The loss of a sense of indestructability, the loss of a feeling of connectedness to one's supportive interpersonal networks, the failure of logic when thinking about the disease, and the disappearance of a sense of control over one's life are all central to the experience of illness. The mix differs from patient to patient, but all four features can be found to one degree or another by the physician who observes, listens, and thinks. By means of clinical material and brief vignettes, Cassell brings to life that which the sensitive physician may discern. This chapter provides the physician with much to reflect upon, and a framework upon which to construct the understanding of illness. More than just illustrating a cognitive structure, however, the author illustrates the many ways in which physicians may use their understanding in the service and humanistic care of patients.

It has often been said that all physicians would be better physicians had they experienced hospitalization, a significant illness, or an operation—a full indoctrination into patienthood. Some physicians have their encounter with "the other end" of the physician-patient relationship. Even if it is as simple as a sigmoidoscopy, barium enema, examination of the genital area, or repeated blood surveys "for some reason," something can be learned about patienthood. More frightening experiences, such as a lymph node biopsy, often strain the physician-patient's need to be calm. Major surgical procedures, fever of unknown origin, a small infiltration picked up on a routine chest x-ray, "suspicious" cells in the Pap smear—the list of truly frightening possibilities is endless.

Most upsetting, however, is the experience of either severe or chronic illness. Here the physician may understand something of shattered omnipotence, disconnectedness, illogicality, and feelings of loss of control.

As Cassell brings it all together for the reader, it may become more "real." Some physicians have the capacity to place themselves in the patient's situation, others do not. A basic premise of this book is that this capacity can be developed or improved upon in most physicians.

What about the person who has abdominal surgery and has the need to show the surgical scar afterwards? How different it is for the attractive, slender woman who loves her bikinis and is undergoing abdominal hysterectomy! Readers may also reflect on how the patient with a permanent colostomy may feel. How important it is for the physician to take time to explain carefully to the patient not only about the care of the orifice, but also what can be expected in day-to-day functioning, including sexuality, exercise, and "noise."

Some physicians are uncomfortable in talking about sex, suicide, dying, or any emotional problem. Some even have difficulty discussing excretory processes with patients. It is hoped that the basic attitude throughout this book will enable the physician to talk with patients appropriately regarding all body functions, physical or emotional. Cassell's vivid way of bringing the reader into the patient's room with him should be a great aid in their regard.

Recent research on the psychological results of cardiac surgery noted that while 90 percent of the patients who survived showed improvement in physical status, more than one-third developed psychological problems that strongly impaired their functioning. Even those with less serious difficulties appeared to be limited in one or more spheres; they did not return to work, resume normal activities, participate normally in their families, or return to normal sexual function. The surgery had improved the hearts, but apparently had not benefited the patients equally.

All physicians have had similar experiences. A man with a myocardial infarction may return to normal cardiac function. But after going home he may experience numerous symptoms, including sticking chest pains, easy fatigue, and poor exercise tolerance. His wife may complain that he is not the same as before the heart attack and not only because he has lost interest in sex. Such a patient may become more placid, but in any case he may lack his former drives and interests. His symptoms may be attributed to depression, and he may respond to antidepressant agents when they are used in proper dosage for a sufficient period.

Or perhaps he may settle down to a career of illness, and become preoccupied by exaggerated fears and crippling concern about the heart.

Why do these things happen sometimes to patients who have been seriously ill, and why did those patients not get the same benefit from surgery that their hearts did?

Every disease has features that are unique because of the physiology or anatomy of the organs involved. The heart can malfunction as a muscle pump, hydraulic system, or electrical system, and the symptoms of heart disease reflect these malfunctions. As that is true of the heart (or the liver, uterus, muscles, colon, and so on), it is also true of the whole person. When a person becomes ill, there may also occur a distortion of his or her relationship to the body, to other people, to work, and to the other aspects of being a person, a private individual, and a member of society. Such behavioral changes are often as much a part of illness as the disease itself. It follows that when sick patients get better, it is not only the diseased organ system, such as the lungs in pneumonia, that returns to normal, but also those activities that are involved in being a normally functioning person in the day-to-day world. We know much more about what happens when organ systems become diseased and then return to health than what happens when people get ill and return to health. Perhaps such a lack of knowledge was acceptable during an earlier period in medicine. Now, when we can do so much more for terribly complicated diseases, and when patients are less likely to die but may be sick for long periods of time before they recover, our lack of knowledge often hampers our patients in returning to their former selves. With a little more help, they could return to normal functioning. It is as simple as that.

Just as a heart or a liver can malfunction in only so many ways, the psychological changes that accompany illness are also limited, and can be described in an orderly and useful manner. The big difference is that our language for describing disease is more precise than the language for describing the "disorders of person" that accompany illness. For the former, we have objective measurements, while for people, our terms are subjective and thus seem "softer" and less real. To put it another way, sick people, no matter what the cause of their sickness, have certain characteristics that are different from those of people who are well. These characteristics are not chance or random events, but are definable, diagnosable, and relatively constant in occurrence. For this reason, the apparently illogical or difficult behavior of the sick is not at all illogical, but is the result of internal and external forces acting on the sick person. The physician must often manipulate these forces to return the patient to health in the same way drugs or other modalities are used to return a diseased part to health.

THE CHARACTERISTICS OF ILLNESS

Sick people suffer a disconnection from their usual world, a loss of their sense of indestructability (omnipotence), a loss of the competence and completeness of their reasoning, and a loss of control over themselves and their world. These features, which will be explored in depth, *are* illness. When they are absent, no matter what the state of the body's integrity, illness *is not present.* Similarly, when one, another, or all these features (arising in the course of disease or for some other reason) are present to whatever extent, then illness continues, again without regard to the body's state of integrity. Furthermore, the effect of each or all of the features of illness on the patient is dependent upon the patient's personality, surrounding social forces, and the nature of the disease or situation that causes them. The features of illness will be discussed separately, but they are inevitably intertwined. For example, problems of reasoning interfere with the perception of the disease process and social relations, and thus reinforce or diminish the force of those features. Similarly, the boundaries among physical, emotional, and social contributions to the illness are also blurred. Keeping these regions separate, while a necessary task in writing about the sick, may interfere with understanding both the patient and the illness.

The Loss of Connection

What I am going to discuss is best illustrated by the cases of actual patients.

> You would have no difficulty guessing what disease Wallace Black has. Sitting up in his bed, he looks somewhat like a white-haired, partly bald, and plucked turkey, because of the wasting of his face, neck, and shoulder girdle. That muscle wasting, which is not quite the cachexia of terminal malignancy, in addition to obvious ascites, is the hallmark of late-stage cirrhosis with portal hypertension. He has been in the hospital for almost 3 weeks. The first 10 days were occupied by diagnostic studies, and in the last week or so a good diuresis has been obtained. The present difficulty is not ridding him of more ascites, but rather that he insists on going home in a few days. Since he is finally making progress, that would be an error. He has offered the usual justification about the bad food and how he would rest better at home. But the real reason is that he is having trouble keeping his business going from the hospital room. While it is often true that a patient's business does suffer during illness, and that should not be dismissed lightly, such is not the case here. Mr. Black is 70 years old and in good financial condition. He has told me that he is a self-made man who has had little education, and that he has been very successful as a broker. Almost no visit to his room goes by without some reference to an important person who just called, or to some business situation in which he alone was able to solve the problem. Mr. Black prides himself on his work and on his social connections, and there lies our difficulty. While he is sick and in a hospital bed, Mr. Black cannot be the person he knows and admires. He knows who he is in part by his relationships to other people and to the world of his business. When he is cut off from those associations he ceases to exist, at least on one level, and that is profoundly disturbing to him.

We are all connected to the world by our relationships with other people and our place in the social scheme. To some, as to Wallace Black, that connection is more important than it is to others; but our interaction with others is vital to the maintenance of our person. In sickness, all these things change. As illness deepens, patients become more and more withdrawn from their usual world, their previous interests, friends, and even their families. We can learn how important this characteristic feature of illness is to our patients by observing how they defend themselves against its effects. (Indeed, that is true of all the characteristics of illness.) It is difficult, if not impractical, to ask patients whether they feel disconnected. They may not know themselves, or be able to verbalize it in that way. But by watching their behavior in the hospital (Mr. Black is always on the telephone), seeing the visitors, and listening to the small talk, we can construct a picture of what is important to the patient. Mr. Black lives near my home, and in the weeks preceding his admission, I would occasionally see him going toward his office. He walked slowly, with 15 liters of ascites sticking out in front of his wasted frame, but he was erect, impeccably dressed, and a figure of respect. I know what effort that continued presence must have cost.

The disconnection of illness is not only social. It may take place over the entire spectrum of being. We exist to the extent that we are connected. Some of the connections are physical, such as the senses, postural reflexes, and proprioception. Even the tearing eyes and the loss of sense of smell that accompany a cold may be disruptive to some. Patching one eye for 24 hours is often associated with irritation, nervousness, difficulty concentrating or coping—disruptions of normal thought and function, despite the fact that sight remains in the other eye. The loss of balance of true vertigo is also profoundly upsetting past the degree of purely functional loss, which is why patients with this sickness may be helped by small doses of phenothiazines in addition to antimotion sickness medication.

Patients are not used to calling these disruptions *symptoms.* They simply do not feel like their usual selves, and when asked about it will point to the eye, ear, or other malfunctioning organ. However, universal recognition of the profound disconnection that can occur is part of the dread of blindness. The losses of connection that accompany interference with the senses are poorly understood when each sensory modality is seen as standing only for itself, like the individual ropes that hold a boat to its dock. Think instead of the empathy one feels for the deaf Beethoven, who has to be turned around so that he can see the audience acclaim the Ninth Symphony. Has he lost only his hearing?

In order not only tc understand their behavior better but also to reduce their discomfort, it is necessary for us to know that patients are reacting not only to the physical symptoms or disease, but to the disconnection itself. Further, since patients may not know why they are irritable, depressed, anxious, fearful, angry, or whatever, they may react to their own seemingly inexplicable behavior by externalizing the source or projecting blame for their feelings onto others. That is why we hear Mr. Black complain about the food and cite the behavior of the nurses and house staff as the reason he must go home. Or, he may say to me that I never explain what is wrong with him, just after I have finished answering his questions in detail. He does not know why he feels the disquiet that he does, and must seek some outside reason for it. Often, the patient's distress will subside as a result of just being reassured that it is normal to feel irritable when, for example, vision is acutely impaired. On occasions, it may be necessary to stress the other ways in which the patient is concerned. The doctor should never simply brush aside patients' concerns about business, work, or social relations as being unimportant, no matter how serious the disease, because to do so is to brush aside the importance of the people themselves. Think how badly you would feel if, because you were ill, you were unable to hold up your part of the duty schedule or do your part of the work, or see patients who had been given appointments. When patients have as little insight as Mr. Black does, explanations may be useless. Then one must balance the danger that the disconnection poses against the need for further hospitalization.

But what threat is posed by something like disconnection? First, it is not too strong to say that anything that threatens the integrity of self, self-concept, or the patient's ability to function as an intact person endangers the patient's physical well-being. *Physical integrity cannot withstand the dissolution of the social personality.* The most extreme example of this is the phenomenon of voodoo death, where the individual is cut off from the group. Friends and relatives share the victim's belief that he or she is doomed. The community withdraws, and on every occasion and by every action suggests to the victim that he or she is indeed dead. Torn from family and social ties and excluded from all the functions and activities through which self-awareness is experienced, the victim yields, and in time dies.

Many of us have seen patients who, when cut off from their world, family, friends, and social ties, simply give up and die from diseases for which recovery might otherwise have been expected. Furthermore, there is increasing evidence that the phenomenon of "giving up"—when the person experiences a sense of helplessness, hopelessness, and deprivation of love or support—may antedate the onset of important organic disease. More commonly, we see an apathetic or depressed patient lying limply in a hospital bed, or we see a patient who will not take medications, refuses diagnostic studies, or insists on leaving the hospital even when obvious danger is involved. The irritation of the staff and its counterarguments merely increase the patient's sense of isolation and disconnection from others, and thus heighten the problem.

But how can we be sure that Mr. Black's complaints about the food and the staff are not the issue, that indeed he is suffering from disconnection and isolation from the people and environmental props that help maintain his integrity of self? As with any other diagnosis, the first thing needed is a high index of suspicion, and the next is listening for the clues. Mr. Black insists that he is going home this weekend—as a matter of fact, on Friday. I cannot, in conscience, discharge him on Friday, but I think I could on Sunday. We talk back and forth for a while, and I ask him why those 2 days are so important. He says, "Doc, I need those 2 days to rest up." Now I know. Rest up? Rest up for what? I turn to his wife and say, "Charlotte, Wallace is going to work on Monday, isn't he?" And that turns out to be the case. He has been working on a deal by telephone, and the papers will be signed Monday. Perhaps they could be signed in a hospital room, but that would not serve the purpose. Wallace Black does not need the money, but he does need the setting and the people around him to tell him that he is Wallace Black. And to him and to many others who are sick, hospitalized, and disconnected from their world, that is more important than merely being alive. We will try to work out something that can meet both objectives: diuresis and improvement of hepatic function, as well as the restoration of his person.

Disconnection may occur rapidly, as in such acute emergencies as myocardial infarction or severe trauma. Suddenly the patient is among people who, well meaning as they may be, are nevertheless strangers. While the patient is lying on a stretcher in a hallway or being moved like an object from place to place, the sense of isolation is heightened. It is also worsened by the lack of privacy in intensive care units, where even the markers of individuality that are usually found in hospital rooms—family pictures, get-well cards, or what-have-you—are absent. It is very common for patients in these circumstances to try to identify for the strange doctor some connection, common acquaintance, or place that connects them. The small talk made while waiting can be used to establish such ties and relationships, thus diminishing the patient's stress. In those settings, there is no such thing as meaningless conversation. It can always be used to serve a purpose. In emergency situations, few needs are as important and as simple to satisfy as making patients feel that they are known.

In chronic diseases or long-term illness, the withdrawal from the world may be gradual. Connection to friends and associates may be replaced slowly by new friendships and relationships that are drawn from within the world of illness. The patient may be alternately frightened by the perception of withdrawal, or disinterested as the horizon shrinks. Leaving the outside world, the sick person begins increasingly to build a new reality that is shared exclusively with the other sick. In the beginning, friends and family may have abandoned the patient, but now the sick person actively begins to reject those from the outside. Even the relationship with a spouse or children may change radically, as everything becomes oriented around the illness. This phenomenon has been compared to the social consequences of aging, with illness producing the social equivalence of premature aging. Thus, in a sense, sickness spreads into the family, causes disruptions, and causes relationships to change in ways of which the members may not be aware. As one must learn to deal with the disconnection of the patient, so must the needs of the family be tended. Once again, from the patient's point of view, these changes may be seen as originating in others and as being directed toward the ill person, rather than, as is often the case, starting with the patient's behavior. Psychotherapeutic intervention may be desirable to diminish the impact of the patient's withdrawal on the family and on the patient. *But it may be an error to attempt to reconnect the patient to his or her former world, since the reality of the illness and its physical and social impact often cannot be overcome.* The new world of the chronically ill exists because it allows patients to reconstitute a self, a sense of their own persons that is appropriate to their new circumstances. In former times the tuberculosis sanitorium, which was described so well by Thomas Mann in *The Magic Mountain,* was an example of the society of the sick. *The Magic Mountain* is worth reading, if only for its superb insight into that society. Today, kidney dialysis and transplant units provide better examples. It is interesting how many patient associations have arisen, associations such as Ostomy Associations, Reach for Life, or Run for Your Life groups that serve the purpose of reconnecting the sick to the world of the well through the mediation of others in the same situation.

The fact that the dissolution of the social personality is often the basic element in the *suffering* of a patient cannot be overemphasized. The sick will tolerate, or even adapt to chronic pain, dyspnea, weakness, or other symptoms without considering themselves to be suffering. If you ask those patients whether they are suffering, they will say that they have pain (or whatever), but are not suffering. But if they perceive themselves as losing their connection to their group—friends, family, or peers—then they will consider themselves to be suffering.

> That point was central in the case of Annette Landy, a 53-year-old woman with increasingly severe chronic obstructive pulmonary disease. Despite severely compromised pulmonary function, she managed to go shopping occasionally, visit friends, or even go to the movies from time to time. She seemed to have adapted well to her considerable disability. Then office visits began to become too difficult for her, and it was evident that her pulmonary function had decreased even further. However, repeat studies, while dreadful, were not worse than previously. She felt, and I concurred, that going out of her apartment had become too difficult, so an oxygen "walker" at home was arranged for her. I was troubled because, despite her taciturn manner and no objective evidence of worsened disease, she seemed sicker. Within a week of my return from vacation, she reported increased cough, phlegm, and dyspnea. I admitted her to the hospital. Her pO_2 on admission was 50mm of Hg. There was little evidence of infection. What had precipitated her respiratory failure? While examining her I noticed shiny, brownish, palm-sized patches about both knees. They came from resting her hands on her knees while urinating—30 to 40 times, day and night! Urinary frequency started about the time I perceived her as worsening, before she could no longer leave the apartment. She urinated so often because she was afraid she would be incontinent. Indeed, that had happened on several occasions. Respiratory failure was probably precipitated by exhaustion. However, both the urinary symptom and her lack of desire to leave her apartment occurred when she began to feel that it was simply too difficult to keep up appearances any longer. She said, "I just decided I didn't give a damn anymore and I didn't care anymore what anyone thought." A devastating idea for someone as well bred and ladylike as this patient—the equivalent of deserting a lifelong mode of behavior and interaction with the world. As in all instances, it is the meaning of the behavior to the patient that counts, not what others believe.
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> Cystometrics were normal. First desire to void occurred at 15 ml, but her bladder capacity was 350 ml. There was evidence of mild trignotis, but infection was not present.
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> In the hospital, with indwelling catheter, adequate rest, increased bronchodilators, and steroids, she began to feel much better. Even though she felt better and was optimistic about going home (although, as usual, slightly apprehensive in anticipation of discharge), her arterial blood gases at discharge were not appreciably better than on admission (although her steroid requirement was increased). Her pulmonary function was marginal at best, and the probability of early death had not diminished. Yet the patient returned home better in her eyes and in mine. What had treatment accomplished aside from teaching her to control the desire to void? She was again one of us, a part of her social group and no longer alone.

It is sad but inevitable when patients die from diseases that we cannot control, but it is an absolutely unnecessary tragedy when the same patients die alone and disconnected from their social world, like a sailor fallen overboard at night.

One other facet of the disconnection of the sick is symbolized historically by Hansen's disease. Here, the sufferer is not only ill, but a threat to the healthy. Venereal diseases are often seen in the same light, even when treatment is simple. With these and other infectious diseases, the bond of the patient to the group is disrupted by the patient's fear of causing sickness in others, which would be a deep breach of social convention. Sometimes one must temper the zeal of hospital epidemiologists when they isolate patients for questionable reasons. The fact of isolation can be an added stress for a patient and should not be done without good reason and without active and continued reassurance.

The tie of the sick to their world, then, may be menaced by the effects of the disease on them or by the danger of their disease to others. Thus, the loss of connection that happens in illness can occur at any or all the places where we connect to our world: physically, as with the sensory disturbances; emotionally, in our connection to those close to us; or socially, where we are connected to the wider world. The physician must be aware of these losses of connection and their danger to the patient's well-being. Dealing with them may mean simple reassurance in conjunction with other treatment, as in the case of the patient who loses vision temporarily, or may be one of the most important aspects of treatment, as with the patient whose ventilatory failure I just described.

The Loss of the Sense of Omnipotence

The next patient, Mr. Fred Bortman, came up from the cardiac care unit a few days ago. He was admitted with a typical history of myocardial infarction, which had been confirmed by the evolution of his electrocardiograms and enzymes. His chest pain subsided rapidly, with no evidence of failure or important arrhythmia. He is 48 years old, white, and a relatively successful middle-level manager for a large corporation; my "typical" patient with a myocardial infarction. He appears healthy, and that is part of the problem in caring for him. In his behavior and in his reaction to the heart attack, he demonstrates another feature of illness, the loss of the sense of omnipotence—a failure of the person's belief in his or her own indestructibility. In health, we take our bodies for granted. Even when one does not like his or her body, its intactness and readiness to go and do are prized. The fact that the world can be a dangerous place that threatens injury or death is known to everyone, but that knowledge is no match for the sense of omnipotence that denies the possibility of bodily damage or death. If there were no sense of omnipotence, who would cross a busy street? Certainly no one would ride a motorcycle. Some individuals have a more strongly developed sense of omnipotence than others, and they are frequently described as fearless, while others who are more fearful have a sense of omnipotence that seems less protective. All physicians have patients who are racked by body fears; every symptom seems to them the ticking of a time bomb.

That was not Fred Bortman's problem. He worked and acted as though nothing could happen to him. But it did. When I see him now, he is talking as if nothing has happened. He tells me that he is not sure that he had a heart attack; he feels fine now. He never felt better. The chest pain that made him call me was not that bad. When I remind him of how severe his pain seemed to be on admission, he tells me that he was "overreacting."

We do not have difficulty identifying his reaction to the heart attack as denial. Indeed, the conversation is reminiscent of many similar interactions with men who have had heart attacks. (Women behave this way less often.) The threat that illness poses to the sense of omnipotence must be met, and denial is one of the most common defenses. A sense of omnipotence, of indestructibility, is essential to *normal* functioning, just as the normal person must feel connected to others and to the social world. Just as the heart muscle heals, so, too, must the sense of omnipotence regenerate. There are, however, some ways of reconstitution that are better than others. The degree of denial displayed by Mr. Bortman is going to get in the way of his return to health.

What this patient is doing is not unusual. I am sometimes awestruck by the power of denial in the face of the most dire symptoms. Patients will occasionally alter their entire life-style to avoid the activity that produces the symptom. Denial is often the mechanism that keeps patients from going to a physician in the first place. Further, denial may be selective—present for one symptom or disease, but not for another. A 58-year-old woman came because of episodic abdominal pain, which was quite typical of gall bladder disease. No other complaints were offered. During physical examination, I was shocked to discover a large fungating carcinoma of the left breast. She said, "To tell the truth, I forgot all about that." Her sister had died of breast cancer (the patient also had cholecystitis).

Angina pectoris and dyspnea are examples of symptoms that are so distressing, not only in themselves but for the meaning they convey about the vulnerability of the body, that patients may go to great lengths to deny their existence. History taking from someone you are sure has angina can be difficult, because occasionally the patient denies not only the symptoms, but also any activity that might produce the symptom. For the same reason, exercise programs for rehabilitation in cardiac or pulmonary diseases have the difficulty that the therapeutic regimen produces symptoms of these diseases, thus constantly reminding the patient of the disease.

On occasion, a patient may report a worsening of symptoms when there is no objective evidence that the disease has worsened. What has happened is that previous denial has failed, and the patient perceives now what was concealed previously.

Symptoms of central nervous system disease are more shattering than most others. Difficulties in speech or memory, hallucinations, and interference with thoughts may strike at the sense of oneself as a person. They are person symptoms rather than body symptoms. In the same manner, disturbances of thought or perception may make patients feel that they are losing their sanity. The same worry about losing their sanity may disturb patients with organic symptoms of disease, such as myalgias, arthralgias, weakness, or fatiguability, when physicians do not believe what the patient reports. The patients are first distressed at the failures of their bodies and then, when they are not believed by physicians, they begin to doubt their own perceptions. Patients with insidious onset of, for example, thyroid disease, myasthenia gravis, or multiple sclerosis, will often report such occurrences as part of the very distress of their illnesses.

The sense of omnipotence is protected by denial even in the language that patients use to describe their symptoms or disease. During a second-year class on interviewing, the demonstration interviewer asked the patient (who was unknown to him) what his problem was. The patient said, in almost so many words, "acute lymphoblastic leukemia." The interviewer never quite recovered, but the patient then proceeded to give the stunned class a lecture on his own inevitably fatal disease. After he left, we all wondered how he could be so calm and self-assured despite his fate. After we had listened to the recording of the interview, the mechanism became clear. All the symptoms and signs of disease were preceded by impersonal pronouns. For example, "you get these spots on your skin" or "one gets bleeding from the gums" or, referring to patients with leukemia, "they often feel weak and listless." On the other hand, all manifestations of health were preceded by personal pronouns, as in "I worked hard all fall" or "we went sleigh riding in the country in February" or "I expect to go home next week." It was as though his internal conception of self was still healthy and intact.

The sense of omnipotence is like a shield around the integrity of the person; it preserves intactness. The symptoms of illness are the enemy of that intactness, and denial is one of its defenses; the completeness of a person extends past the physical boundaries of the body. A person is also his or her beliefs and ideas, as well as usual activities, habits, and patterns of behavior. That is why sometimes, when you are about to hospitalize someone who has been taken with serious illness suddenly, the person will say, "I can't go to the hospital. I have to go to my exercise class tomorrow." The comment is inappropriate to the seriousness of the situation, but the patient does not seem aware of how silly it sounds. Going to the exercise class is part of the weekly routine. It is not so much the content of the activity that is important—although exercise may play a significant part in the image of self—as it is the loss of part of oneself. Nonetheless, patients are usually aware of the symptoms they deny, but to accept the symptoms would demand a change in self-image, in the sense of self. Thus, if you listen closely, you will hear patients depersonalize their symptoms by doing what the patient with leukemia did—using impersonal words. *The* pain, not *my* pain. A woman with a pulmonary embolus was giving the history of the thrombophlebitis that preceded her present illness and said, "*My left leg*" (the patient's own leg, part of herself) "which is *the bad leg*" (no longer "my leg," but a bad leg that is not part of myself) "from the vascular point of view," (not bad from her point of view but from some outside, abstract position) "had a thrombophlebitis in it." (She did not have thrombophlebitis—*a* leg had *it*.) She could have said, "I have vascular problems in my left leg and I got thrombophlebitis." You will have to listen very carefully because such impersonal usages are so common that they are difficult to hear as distinct entities. The difficulty in picking up the language attests to the normalcy of the phenomenon. The language distances the patient's intact self from the phenomenon that threatens the self. Women virtually always refer to their breasts as "my breasts," but when about to have a mastectomy, they will commonly talk about "the breast." More strikingly, after the mastectomy, they usually refer to the remaining healthy breast as "the breast" rather than "my breast." Months after the mastectomy, the healthy breast again becomes "my breast." The fundamental point is that the self, the person as seen by oneself, must be preserved at all costs, and illness threatens that sense of self. Thus, the sense of omnipotence functions to maintain certain aspects of self-image.

Ultimately, as sickness becomes worse, all defenses fail and the patient is forced to acknowledge the body's failure. Previously powerful and now helpless, previously sure and now untrustworthy, the body is seen for what it is: fragile and defenseless against injury.

The problem with denial as a defense against the recognition of illness is that its opposite face is frequently panic. The sick person has refused to accept or even consciously recognize all symptoms of disease, even the trivial, but when illness overwhelms, the patient begins to react with great fear to all the symptoms that had previously been denied. The panic comes not only because of the sudden awareness of illness, but *also because of the loss of the major defense mechanism.* To be both sick and defenseless is terrifying. Denial can cause major problems for a physician. The patient does not accept the facts of the illness, and thus may not take medications, go for needed diagnostic studies, or return for the follow-up. I am sometimes uncertain what to do when a patient behaves in this manner. I know how dangerous it can be to breach the denial forcibly by telling the patient in no uncertain terms what the situation is. I do not want to use stark language that would be avoided with the most stable person. If I use it, the patient will not act, but will be paralyzed with fear by what I said, and that was hardly my original object. Furthermore, by using such straight language I become the enemy (after all, I frightened the patient, not the disease).

In these situations, I try to provide an alternate defense for patients. Overintellectualization is a useful substitute that can be encouraged by long intellectual discussions of the disease or symptom, as though we were talking about someone else's body, and that can point the way to the desired action. In engaging in such discussions, I am employing the same mechanism described above—depersonalizing the body part of symptom by using impersonal pronouns. I might say, "Fluid in a chest like that often comes from the reaction of the chest lining to an inflammation. It is important to find out what the chest wall or the lining is reacting to in order to prevent the lining from making more fluid and compressing the lungs." The fact that what afflicts the lungs afflicts the person is not mentioned.

At other times I let more time pass, when that can be done safely, because I know that sooner or later the patient will be forced by the symptoms to recognize the illness. Panic may follow, but now I am not the one whose bad tidings caused the panic, but rather the one who offers safety.

After Wallace Black, the patient discussed earlier, went home, his diuresis continued. One day he called, weak-voiced, from his bed. His weight that morning had been 116 pounds. (His weight when leaving the hospital was 126 pounds, and his normal weight about 155 pounds.) He said he was dying—wasting away and dying. I saw him at home. The abdomen was flat, almost free of ascites, but there had been no further muscle wasting. He went on for awhile about his pitiful state. He was finally ready to listen as he had not been for all the months of his illness. So frightened was he by the sudden awareness of his condition and by his interpretation of its fatal meaning, that what I had to say about his cirrhosis seemed to be a reprieve. Together, we could plan a realistic therapeutic regime. Fred Bortman is not yet there.

Denial is by no means present in all patients with myocardial infarction or other serious illness. On occasion, patients appear to be completely aware of the danger of their situation, or the bleakness of their future. Not surprisingly, such awareness is frequently followed by depression. Those patients may appear agitated, apathetic, or merely bland. It is distressingly common to find every emotion that patients evidence labelled as "anxiety" and treated with antianxiety agents. In the first place, all emotion does not have to be "treated away," as though it is inappropriate to be sad or depressed after serious illness. Rather, the reasonableness of the response and its reasons should be acknowledged by the doctor. As will be discussed later, the patient is beset by uncertainties about the future, many of which can be put to rest by the doctor in a few minutes of conversation. False optimism is neither desirable nor desired by patients who are alert to their situation—they see through it quickly. But what is necessary is an attempt to elicit the concerns that are *specific* to each patient, followed by information that the patient needs in his or her own terms. Second, sedative drugs may depress the patient further by restricting psychic and physical activity, which may increase the patient's sense of being in a straitjacket.

When speaking with Mr. Bortman, I discovered that his heart attack had occurred one year to the day after his wife died. His relationship with his wife had been extremely close, and he has felt lost since her death. One of his two children fled the home and married unexpectedly two months after her mother's death, and the other daughter left college to come home and care for him. Aside from telling me these facts, he does not want to talk about his wife, the emotional impact of her death, or the possibility that he might be depressed. The anniversary timing of his myocardial infarct is to him "coincidence." Mr. Bortman's denial, then, extends beyond physical illness and into his emotional life. When denial is present in psychological matters, we often speak of a patient as having no insight. But the problems presented in caring for such patients are the same as those presented in other cases of psychological denial. Just as it will be difficult to get Mr. Bortman to accept a program of cardiac rehabilitation, so too are the chances minimal that he will seek needed psychiatric help.

A number of studies have reported the anniversary phenomenon—death or illness occurring on the anniversary of the death of a loved one, who is most commonly a parent or a spouse. The finding is interesting in itself, but it points to something of broader significance: the association of illness in the patient with illness in other family members, who are generally the parents. Patients commonly tell us that they know that their joint pain is arthritis because their mothers or fathers had arthritis. As I said earlier, the boundaries of a person do not stop at the limits of the body. We often speak of identification with a parent as though the connection to the parent occurred solely in thought. In fact, however, the person may think or behave as though his or her body were a literal extension of the parent's, and display the same physical strengths or weaknesses, or be prone to the same diseases, as the father or mother. (A child may identify with either parent.) We acknowledge this, generally, by inquiring specifically for a family history of heritable disorders. But it is important to go beyond such diseases and inquire whether the patient knows of any diseases or health problems that "run in your family or which are of concern to you because of your family history." Unless specifically asked, patients will often not offer such information because they are unaware of its importance, or even on occasion because they are embarrassed at what they perceive to be a "nonrational" influence on their behavior. On the other hand, the link of their illness to that of a parent may offer comfort. A 49-year-old physician had what he thought was an inexplicably prolonged upper respiratory infection and finally went to see his own doctor. When told that he had hay fever (a diagnosis that should have been obvious to him) he said "But that's impossible, I'm 49." He did not seem satisfied when told that it did not matter how old he was. But then he said, "What's the matter with me, I forgot all about it—my father and sister had hay fever." Now hay fever was acceptable.

While that is a trivial example, more serious situations exist when patients act as though history is prophecy, as though if the parent died of (say) congestive heart failure, it is inevitable that they, too, will die of congestive heart failure. Because of that belief, they may not carry out simple and obviously effective treatment. Since the patient may not be aware, for whatever reason, of the association with the parent's disease, the information must be actively sought. Often merely pointing out the association and showing what can be done for patients to change their future is sufficient to avoid an otherwise fatal outcome—it is often a matter of a few minutes conversation.

Fred Bortman's illness extends to his family. Indeed, he was referred to me by his sister-in-law prior to his heart attack (but he did not call until he developed chest pain) out of her concern for the disruption of the family following the death of his wife. His heart attack has compounded the family problem. The wife on whom he was so dependent is dead, but her place has been taken by the daughter who left college to care for him. With his illness, the burden on the daughter has increased and I suspect that she will have difficulty leaving her father again and resuming her own life and career. Similarly, the flight of the other daughter suggests trouble. I call it flight because the period of mourning for the death of a parent is usually longer than two months; usually families draw together rather than disperse during that period. Furthermore, she married someone whom she had not known prior to her mother's death. This added to my belief that her actions were precipitous. One may speculate about the reasons for her departure and marriage—that she was escaping the burden that ultimately settled on her sister. But those would be speculations that could neither be confirmed nor acted upon. Indeed, what action is possible, even after we recognize how physical illness has caused widespread family disruption? Frequently, perhaps usually, serious illness in an individual leads to difficulty in the family unit, but often all the family members are not our patients, or they do not seek our assistance, or they may even be unaware of the extent of the problem or its source. Where possible, referral to a psychiatrist or family agency may be very helpful. But when that is not possible, we are left treating the only family member to whom we have access—the patient. In Mr. Bortman's instance, his family will be best served if we are able to rehabilitate him to the point where he feels whole again—not just from the heart attack, but from the death of the wife. Because of his denial and his lack of insight, the best approach, referral for psychotherapy, may not be possible—he does not think he has an emotional problem. Nonetheless, such treatment should be suggested when appropriate. Using psychotropic drugs, such as tricyclic antidepressants, probably is also not feasible. To be of value, these agents must be used in adequate dosage for a long enough period. Drug side effects are inevitable, if they are only dry mouth and some initial lethargy, and Mr. Bortman will not tolerate symptoms produced by drugs whose aim is to relieve a depression that he does not even think he has. Here, as in so many instances, if we are to be successful *we must start where the patient is.* In planning his treatment, we are forced to work from his point of view of himself, his illness, and his family, since he will not accept our view. We are left, then, with only his body to work with and somehow, by doing that, we hope to have an influence not only on his heart disease but on his family unit.

What is Mr. Bortman's understanding? He tells us that he does not believe that he has heart disease. Rather, he thinks that he was very upset after his wife's death and because of that he worked himself into exhaustion. His present illness resulted, he says, because he was "overtired." Furthermore, he used to be very active physically, and after the death of his wife he stopped playing squash and let himself get "out of condition." In the subsequent discussion I use his viewpoint. I do not stress his heart disease, which would further weaken his failed sense of omnipotence and breach his denial (in addition to providing more reason for him to be dependent on his daughter). Rather, I lay stress on his physical vanity and his view of himself as a powerful man on whom others depend. That, after all, was the image he used to pretend to himself that he was not so dependent on his wife but rather vice versa. In outlining an exercise program for cardiac rehabilitation, I emphasize the state of fitness he used to enjoy, and make it clear that he can be in even better condition in the future. In the months to come I will stress the same points repeatedly. As he achieves maximum fitness in a regular running or other aerobic exercise program, there is a high probability that his body will tell him that he is what his body is: strong, trim, functional beyond others of his age and medical background. Body pride based on real achievement has a powerful effect on self-image. We know the task will be difficult. Keeping him running, and handling the symptoms that arise without either reinforcing his physical fears or allowing him to go beyond prudent limits will test my ingenuity. But the alternatives are increasing dependency, cardiac fears, and a trapped daughter—to say nothing of recurrent myocardial infarction. With Fred Bortman, as with other patients, we must start where he is and work within his own worldview to achieve the goal of a return to health for both him and his family.

The Failure of Reason

These patients asked many questions about their illnesses. Some of the questions I had answered during previous visits, and yet they came up again. Your own experience will confirm that, even after you have provided lengthy and apparently lucid explanations in response to patients' queries, the patients will ask the same questions again, as though you had never spoken to them. With good reason, we believe that patients should know what is happening to them. Informed patients work better with their physicians. Yet these experiences make us wonder, occasionally, whether sick people are capable of understanding the complexities of modern medicine. Indeed, it is true that the ill have problems in reasoning. The difficulties arise for two reasons. The first is that sick persons cannot, because of the nature of thought, stop thinking about their illness, but they lack the knowledge about the body and disease that is essential to understanding their circumstances. The second problem is that in profound illness, the very nature of the thinking process changes without the patient's being aware of the change.

Normal thought strives continually to understand events even when the dynamics cannot be controlled and the real significance of those events refuses to reveal itself. An event is merely something that happens, a change from one state to another. Illness also is an event, or series of events. Thus, patients attempt to understand what is happening, but their knowledge is inadequate, and the things that are happening seem beyond control. One of the ways we maintain control of our world is by knowledge. Certainly, as physicians, we maintain control of our cases in part by knowing what is happening. Consider a patient who is getting sicker, in a case where death seems inevitable. Think of how differently you would feel if you understood the disease and what was happening to the patient, as opposed to having no idea what was going on. Where your knowledge was adequate, you might feel sad that the patient was dying, but you would accept it and consider yourself in control. On the other hand, if you had no idea what was transpiring, you would probably feel desperate. The crucial difference between the two alternatives is not what is happening to the patient, but your sense of the adequacy or inadequacy of your knowledge. Our knowledge is part of ourselves. When it is incomplete, we feel incomplete. In abstract matters or those of little concern, where information is inadequate, one can merely stop thinking or change the subject of thought. But in illness that is not possible. Each symptom, each body sensation or event demands thought. Because the presence of symptoms maintains a threat, thought cannot stop, nor can the subject be changed. Rather, new information must be sought, and where that is lacking, repeated reinterpretations of existing material are constructed, with new content from memory and emotion added to make up for a deficient reality. Rather than moving away from danger, each new interpretation seems to increase the patient's fears and sense of threat. It is as though some force was always pushing toward an abyss.

The next patient will demonstrate the importance of understanding the relationship between the reasoning of the sick, and the phenomenon of illness. Further, this case will illustrate how such understanding can be used to reduce the sick person's burden.

> Mr. Fanton is 24 years old, and he is here for the second hospitalization for an undiagnosed illness within a month. About 3 months ago he developed generalized, tender lymphadenopathy, accompanied by malaise, intermittent headaches, and transient and variable pains in the lower extremities. He was seen by several physicians before he consulted me, and he had received two adequate courses of tetracyclines. Laboratory studies at that time were extensive, appropriate, and uniformly negative. He was admitted for an axillary lymph node biopsy, which also was not diagnostic. Two weeks later his condition had not changed and he was readmitted for further diagnostics and repeat biopsies. Again, all the very extensive tests and biopsies were negative. Even his sedimentation rate was normal. As he had reported, he was not febrile, and moderate generalized lymphadenopathy (no longer tender) and mild splenomegaly were present. He had been informed of his negative test results as they became available, and yesterday he was told of the negative biopsies. He has been becoming increasingly depressed since the first hospitalization, and now the depression is obvious. He tells me how frustrated he is, and how much worse he feels than he did when he came to the hospital a week ago. His appetite is poor, and he is occasionally nauseated. He reports an inordinate amount of pain from the biopsy wounds.
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> He says that he would be better off if he had a lymphoma and was receiving chemotherapy. He knows about lymphoma because his father has lymphosarcoma and is receiving chronic chemotherapy. Further, his father has had repeated complications in therapy. Why would that state be better than his? "Because anything is better than not knowing, and besides I know that's what I have." Clearly, the uncertainty is a major source of his distress, not only because that is what he says, but because virtually all patients with undiagnosed disease and confirming symptoms behave similarly. Furthermore, he, like many patients, continues to question all the doctors in a way that increases his uncertainty by exposing theirs. As the conversation continues, he says that perhaps I believe he is making it all up, that he is not ill. Or perhaps the illness is psychological, that deep down he wants to be sick like his father (the modern patient is often very sophisticated). On the other hand, he thinks perhaps the disease is from the damage he did to his body when he used to take hallucinogens. Or possibly it is a virus that is still in his system from a previous illness. At each almost contradictory step, he pays little attention to my answers or reassurances, and tells me that I do not know whether he is wrong because I do not know the diagnosis. When we discuss his return to work (he had been on sick leave for almost 2 months), he insists that he cannot return to work. I point out that if he did have a lymphoma, and was on chemotherapy, I would be urging him to return to work. It compounds his problems to lie in bed at home when his symptoms do not warrant that. He says he would return to work if he had a lymphoma, but he cannot because he does not know what is the matter with him. Unless his symptoms and signs subside promptly and completely, I will indeed have greater difficulties caring for him without a diagnosis than I would if he did have a lymphoma. He and I both know that the possibility of lymphoma remains despite the negative studies.

How interesting that this patient conceives himself to be more disabled without a diagnosis than he would be if he had a lymphoma, the disease he fears! While the problems raised by this patient are extreme, they provide an opportunity for a closer look at the thinking of the sick patient.

Notice the number of possible causes for the illness that he raises almost simultaneously. He proposes that it came from damage to his body from previous drug usage. Patients will suggest other behaviors that they conceive of as being "bad" or "wrong"—overwork, poor diet, stress, or sexual practices, for example. He suggests "A virus that remains in the system." Other commonly expressed causes are toxic exposures—food additives, air pollution, work-site exposures, and so forth. Fear of malingering may be expressed as "perhaps there is nothing wrong with me at all," which is sometimes said in the presence of undiagnosed high fever or other obvious abnormality. Other psychogenic etiologies that may be either sophisticated, as in this instance (identification with the father), or quite simple are sometimes offered as possibilities. In advancing this glut of possible causes, Mr. Fanton is doing what all patients do, seeking cause.

It is important to realize that when we think of events we must inevitably think of cause at the same time. When I enter a room that is well known to me, and see the furniture arranged in its typical fashion, I do not "think" about the room. I merely recognize it. Should I return home one evening when no one has been in the room and see a piece of furniture in a different position, recognition is not sufficient. The change is an event, and I must search for cause. Finding none, I might think of an intruder. Similarly, a strange sound can drive someone wild until its source is identified. In illness, symptoms always represent a change whose cause must be sought. Generally, cause will be looked for outside the person—infection or trauma, for example. When such causes are not obvious, patients will inevitably look within themselves for cause, as did Mr. Fanton. Often more than one cause will be attributed, and will always include something the person did, including what the unconscious may have done. That is why we so commonly hear patients ask whether their disease is due to "nerves." Cause, in other words, may be seen by the patient to occur at several levels: the outside world, the patient's behavior, or within the patient's mind.

The one unacceptable cause is fate. That some things just "happen" is an intolerable blow to the sense of omnipotence, because acknowledgment of that fact would render the person helpless. Remember that the biblical Book of Job is occupied in large part by Job's friends' explanations that he was being punished because of something he did wrong, whether or not Job wanted to acknowledge that. A capricious God or fate is intolerable.

In short-lived, acute, or unimportant diseases, the doctor does not have to know what is occupying the thought of the patient, although questioning will reveal the same processes I have described. In chronic disease or in serious long-lasting illness, however, *the patients' reasonings and the behavior that is based on them influence the course of the illness.* Compliance with instructions in regard to medication, bed rest, activity, return to work, and other aspects of therapy is influenced by what patients believe to be the cause of their illness and its manifestations, and equally by their understanding of the disease process.

The question is simple. Do you want patients to act on their understanding of diseases and their causes or on your understanding? If you want their thinking and actions to be based on your knowledge, then matters must be explained to them in detail. Patients in this era do not undertake complicated regimes or alternatives in life-style simply because they are told to do something (if, indeed, they ever did). For your explanations to be effective, they must start with the patient's existing concepts, and the information you provide must relate to the patient's existing knowledge. For that to be possible, you must question patients about their concepts of the disease and its course, and respect their answers, no matter how odd they sound. Simple questions, like "What do you think brought on your condition?" or "Do you have some ideas about what makes your pain (or shortness of breath, weakness, swelling, or what-have-you) worse?" are often sufficient to produce enough information on which to base other questions. Some beliefs or fears, such as the fear of cancer, recur commonly and will allow you to offer some suggestions when patients are hesitant to voice their concerns. The following example is typical of how the patient's beliefs about cause can become the basis for continuing illness, and can provide the point at which the doctor may intervene.

> A 67-year-old man was admitted to the hospital because of an old urethral stricture with secondary urinary symptoms. The work-up was given urgency because of continuing abdominal pain and progressive weight loss of several month's duration. A barium enema before admission had shown diverticulosis. Intravenous pyelography, cystoscopy, and retrograde pyelography revealed no new disease, although on the basis of the history of significant weight loss, a malignancy was suspected. Because of the negative findings, a medical consultation was called.
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> One brother had died of cancer "all over," but otherwise his family history was not helpful. His wife was alive, and he had children and grandchildren. Originally he had been quite heavy, but he had lost more than 20 pounds during the illness. Earlier, he had noted that the pain, which was quite severe and cramping and more prominent in the left lower quadrant, was clearly aggravated by eating. Because of that, he ate smaller and less frequent meals. Recently the pain had become much less severe and less frequent, but he had continued to avoid food. During the month before admission, he had slept poorly and had become less interested in things and less active.

How prominently the pain figured in the history and in his discussion of his situation, despite the fact that at present it was quite minimal! Indeed, it took many questions to establish how little pain he now had compared to months ago. In his thoughts, in other words, the pain was still a prominent symptom although in fact it was now minor. He had been told that his x-rays and tests were negative. There were no findings on examination, and the only evidence of weight loss was the change in belt notches. This patient is no different from any of us; because of persistent abdominal pain and weight loss, he was sure he had cancer. In fact, what had happened was this: The abdominal pain was aggravated by eating (quite typical in diverticulitis), so he ate less and less often. Because of that he lost weight. He attributed the weight loss to the disease, not to his change in eating habits, and after adding things up, became convinced that he had cancer. But why did he not improve when told that the tests were negative? Because his thinking included another belief common among patients, particularly those of his age and background—doctors do not tell patients the truth about cancer.

When I asked him what he thought had been the cause of his condition, he answered that he did not know. He was not a doctor. I suggested that most people with his symptoms would think they had cancer. Had that not entered his mind? He admitted that the possibility worried him. I told him that I had examined him and reviewed his x-rays, and that he did not have cancer. But saying that was not sufficient, so I related what I believed to be the chain of events, including the fact that patients often believe that doctors do not tell the truth about cancer. I also pointed out that his pain had subsided, which would have been unlikely if the cause had been cancer. But why had he not been able to reassure himself with the same information? Because once his thoughts had seized on cancer as the cause, all other information was used to serve that belief. What did not fit his fears was dismissed. He, like all of us, believed the worst. When I saw him the next day at lunch time he was a different man. His appetite had become voracious, which served to reinforce my point. Often such patients will not acknowledge overtly that they have had the fears that I suggest were present. They are afraid that the doctor will consider them a "mental case." As in this instance, one can suggest that other people in the same situation, or even you, the doctor, might have felt that way. It is sometimes difficult in the setting of physical illness to suggest to patients that you know what they are thinking; they may view that as an intrusion on their privacy. Other patients will feel very comforted to know that you understand them. But even in the patient who denies that he or she ever had such a fear, the effect of correct interpretation will usually be beneficial. It is not necessary that patients agree with you; it is only necessary that they get better.

The case should make clear that what the patient thinks and how the patient reasons are as much a part of the illness as is the disease. Consequently, what the doctor says and how it is said can aggravate or ameliorate the illness process.

What we have been discussing is similar to the problem of truth telling that is discussed in Chapter 30 on the care of the dying—the problem of uncertainty. Both Mr. Fanton and the man with weight loss and abdominal pain demonstrate the effect of uncertainty on patients. When patients do not know the cause of their illnesses, they do not know how to act. Furthermore, lacking any defined understanding of the process of the illness or its outcome, they begin to associate symptoms with events in their lives or in their thoughts, events that have no basis in fact. Because these associations have no factual basis, they do not hold true from day to day, and uncertainty increases. Ultimately the patient becomes trapped in all the contradictions, and a sense of helplessness ensues. The feeling of helplessness can be extremely dangerous. It has been repeatedly documented that patients' sense of helplessness can precede the worsening of their diseases and lead to the "giving up" complex from which, in serious disease, death may follow. Furthermore, a sense of helplessness is not unique to illness, but occurs in many life situations. Here, too, there is considerable evidence showing that illness can arise in the previously well when they become overwhelmed by helplessness.

The role of physicians in the face of uncertainty and helplessness is clear. In providing knowledge of cause, process, and outcome, they provide both certainty and a basis for actions. Doctors are overly aware of their own uncertainties and of the fact that decisions in medicine are based on competing probabilities. Because of that, they are hesitant to reveal those facts to patients. But the patient is in an endless sea of contradictions, which is much worse than that of the doctor who faces perhaps two or three possibilities. Thus, even the doctor's doubts and questions seem like a rock of safety to the patient, because each possibility entertained by the physician opens an avenue to action. And each action is based on reasoning and evidence—things that are outside the patient. It is not necessary for doctors to make statements that falsely hide the uncertain future. It is possible to stress what is most probable at the same time that other possibilities are mentioned. If the other possibilities are serious or unpleasant and must be discussed, then the patient should be told at the same time what will be done if the serious alternative occurs. To the patient the dangers are unlimited, so that whatever the physician says *must put limits on the threat.* Statements that point out that the future is unpredictable should be avoided. It is rare that the future for a particular patient is totally unpredictable. We should not worry that the future will prove our statements wrong. Patients know that doctors are fallible, and even an incorrect prediction (within limits) is often better than no prediction at all.

A common example would be a conversation with a patient who has had a myocardial infarction, like Mr. Bortman. Such patients want to know what their future will be but we may not be sure whether they will have angina or congestive heart failure after they resume their activities. However, we usually have a pretty good idea from their past history and their course in the hospital. I might say, "It looks to me as though you will be able to resume your life pretty much the way you did before, and that your heart disease will not limit your activities. I want you to start an exercise program, in which case you may be in better shape in a year or two than you have been in many years. Sometimes people who have had a heart attack get chest pains, or angina on effort, afterwards. I don't think that will happen to you, but it is possible. If it does, I will be able to give you medication that is effective in controlling the symptoms and may still allow you to participate in the exercise program. Another possibility is that your heart may not work as effectively as it did in the past, in which case I will be able to give you drugs that strengthen the heart and reduce its workload and allow you to get on with your life." That is, of course, a monologue in a situation where there is usually a dialogue. A dialogue is necessary for the patient to make clear his or her questions, life demands, or understandings, and for the doctor to make sure the patient understands not just the words but the meanings. Not uncommonly, patients will seize on the worst possibility, no matter how unlikely, and act as though you had told them it was their inevitable fate. The importance of something to all of us is not how likely it is but how threatening. (Think back to your fears of flunking out of medical school.) When as part of your discussion it is necessary to relate some remote danger, and the patient acts in that manner, you can say that although some people just have to have something to worry about, the realities are those you have just listed. Do not get driven to denying that the danger exists. If it is said and then denied, its importance is heightened. The principles here are clear, as in the case of the dying (see Chapter 30). Information should reduce uncertainty, increase the patient's ability to act in his or her own best interests, and strengthen your relationship with the patient.

Reason fails the sick for another important reason. When Piaget's tests for the conservation of liquid and area are administered to the profoundly ill, their responses are similar to those of children who are 7 or 8 years old. In Piaget's tests, two short squat containers are filled with an equal amount of water and are shown to the patient, who is told that the volumes are equal. While the patient watches, the content of one of the containers is poured into a tall, thin tube. Then the patient is asked which contains more liquid—the tall, thin tube or the short, squat container. The patient will usually respond that one of them, often the thin tube, has more liquid! Sometimes patients will say that they know that both *must* be the same but that the tall thin tube *has* more fluid. These patients may be completely oriented in all other dimensions. The same findings have been reported for the aged.

If one looks further at the psychology of children of age 7 or 8, other similarities with the ill are apparent. The most evident is the inability of very sick patients to *decenter*—to see themselves and their actions objectively in relation to their physicians, families, other people, objects, and events. Simply put, ill patients often interpret every action of others as being directed toward them. If the nurses are slow, it is because the nurses do not like them. Patients commonly ask whether I am angry with them or whether something is wrong between us when I appear irritable, even though the irritability has nothing to do with them. The self-centeredness of the sick is not within their control. It is an inherent characteristic of the state of serious illness, just as bronchoconstriction is part of obstructive pulmonary disease. For this reason, doctors must learn to be aware and consciously choose their words and actions in the presence of the sick patient. Their words will never be taken casually. They will be interpreted by the patient in relation to him- or herself. It is not a novel observation that regression occurs in illness, but it is vital to understand that regression is not an abstraction. We must wonder whether patients who are reasoning in the fashion described are best able to understand complex medical information, make definite decisions about their treatments, or sign truly informed consents. How then to square the importance of providing knowledge to patients with the limitations of their ability to reason?

As I have shown, the ill are continually attempting to understand cause and outcome, and because of their need to understand and their self-centeredness, they interpret almost all information in terms of their situation. It is all the more important, therefore, that they be provided with the facts by their physician. Furthermore, these explanations must be concrete, as detailed as is necessary for the patient to understand, as free of abstractions as possible, and ideally should be accompanied by a sketch or other graphic. Simple and clear does not mean simplistic, nor does it mean talking down. Sick people may not be aware of the change in their reasoning, but they are more than usually aware and insulted when they are treated like children. The explanation to a patient with preexisting heart disease, who develops congestive heart failure because of fluid overload after common duct exploration, would sound like this: "Because of the heart trouble you have had for years and which you know about," (the reference to something known limits the danger—nothing new has occurred) "the extra intravenous fluid you received during and after your operation was too much for your heart to pump. Because of that, some of it has backed up into your lungs, and that is why you are short of breath. We can easily make that better by giving you this drug to make your kidneys get rid of the extra fluid. You will be better in a couple of hours." That, or some variant, is better than "You've gone into congestive heart failure from fluid overload and an inadequate cardiac output. The diuretic will increase your urine output." The words congestive heart failure, fluid overload, and cardiac output are not merely technical terms, they are abstractions. Diuretic and urine output are technical terms.

Similarly we are all aware of the need for informed consent but also of its difficulties. Therefore, the patient must have the necessary information presented in a manner best calculated to achieve understanding. A mere recitation of the facts does not meet the overriding moral, legal, or clinical demands.

The Loss of Control

The patients' perceptions of their altered physical being, and perhaps never-before-experienced sense of fragility, loss of connection to others, and altered patterns of thought, add to the sufferings of illness. These features of the sick are not abstractions. They are concrete changes that alter the very rules of human existence. It is this perception that adds to the next and perhaps most potent fact of severe illness, the loss of control.

To be or to perceive oneself as helpless is one of the most frightening of human experiences. Yet helplessness is the cardinal fact of severe illness. The sick do not *do.* They are done to. It is not merely that the infirm body will no longer obey commands, but rather that at every interface of the person with his or her world, there are obstacles to the control of that world. The characteristic features of illness that have been discussed are contributors to the loss of control, while psychological defenses and coping mechanisms such as denial, suppression, regression, rationalization, projection, sublimation, intellectualization, and so on, are attempts to protect the patient from the helplessness or its perceptions.

Throughout this chapter, I have tried to show how the disability of the sick comes not only from specific disease manifestations, but also from the changes that occur in the relation of patients to themselves and to their self-concepts, to their social existence, and to their ability to control their own existence. To understand this, one has to break down, or at least set aside the usual distinctions between physical, psychological, or social.

Mr. Black's muscle wasting, ascites, and weakness clearly result from altered hepatic function, and can thus be seen as organic or physical. Dietary or diuretic interventions may improve his situation. But when he leaves the hospital and returns to work prematurely because he is trying to maintain intact his sense of himself as a person, and as a consequence his ascites increase again, will that be a psychological, physical, or social problem? As the distinctions become blurred, our knowledge of how and when to intervene to make Mr. Black better becomes much sharper. We can do something to diminish ascites. We can intervene at the level of his altered reasoning by making cause, process, and outcome clearer (in the light of his wasting and weakness, he too was sure, as was his family, that he had cancer), and thus reduce uncertainty. Or we can teach him how to obtain maximum social function by appropriate use of rest, medication, and diet in order to preserve his sense of himself. All levels of intervention will make Mr. Black better within the ultimate constraints of his liver disease, by returning to him as much control as possible. And return of control will not be accomplished by merely treating his liver or by treating only his psychological or social problem. Obviously, in acute diseases such as pneumococcal pneumonia or appendicitis, the best way to return control to the patient is to cure the disease. But today we are more often faced with the kinds of cases discussed in this chapter, where no easy or permanent cure is possible. We have three kinds of tools available to make these patients better: (1) our knowledge of disease and medical technology, the things usually associated with the doctor's job; (2) our knowledge of the effects of sickness on the person, which is what we have discussed in this chapter; and (3) the thing that allows the other two kinds of knowledge to have an effect, namely, the doctor-patient relationship. Throughout this chapter I have used the personal pronouns *I* and *we* to refer to me and to other doctors, and I have discussed actual cases. We all know enough by now to treat each patient as an individual—to individualize care. But each doctor is also an individual, an *I*. I stress this because the illness phenomena presented here are subjective and are not easily measured, except indirectly, and therefore they depend on the person of the perceiver, unlike the reading on a sphygmomanometer. The process of returning control over their circumstances to patients requires a physician who is in control. That is, the doctor is the patient's surrogate—returning the connection to the world, supplying an alternate method of reasoning, and acting for patients where they cannot act for themselves. Control for physicians comes in part from being able to see what the patient sees and know what the patient knows, and from being able to put themselves in the patient's position without being overwhelmed by fear or sadness, and without dying with each patient who dies. The process of learning that control starts with using yourself to know and feel what the patient knows and feels, and learning to distinguish within yourself what comes from the patient and what comes from you. That is a difficult task that takes time, but it takes no more time to learn the basics than it does to learn to use a stethoscope, or teach one's hands to feel pelvic organs. The first and necessary condition is understanding that the information gained is as important as that coming from a stethoscope. With that in mind, let us return to the patient's loss of control.

Some symptoms, such as the loss of bowel or bladder control, are worse than others because, harkening back to infancy as they do, they symbolize for the ill the sorry, helpless things they have become, likened to babies by themselves and by others. We are often not aware of how the everyday world is adapted to the needs of the normal body. The height of the bus step, curb, or table; the way typewriters work; the way food is served; bathrooms; the length of meetings; doorbells; doorways; and countless other details in the world around us are invisible only to those who are well. Let a knee joint stiffen or give pain, a hand wither or tremble, or even chronic itching appear, and the world no longer works so well. Then those invisible details become obstacles to be surmounted.

In the same manner as the other factors that make up illness, the loss of control extends past the physical into the social and emotional life of the sick person. When the ill patient can no longer work, not only is his or her income threatened, and with it control of the world and image of self associated with economic power, but more importantly, that patient may no longer feel needed or important to others.

In emotional relationships as well, the helplessness of illness can be destructive. We know ourselves not only by our work and by our place in society, but also by those whom we love and by those who love us. But loving relationships, to whatever extent they may be possible in each individual, demand the ability to give as well as to receive. Helpless people, who have no sense of their own presence or power, feel that they are valueless, that they are objects neither deserving of love nor able to give it. Indeed, they may feel diminished by the love of others as it emphasizes, in its necessary one-sidedness, the patients' likenesses to a child.

It is obvious that helplessness and loss of control, in common with the loss of connection to the world, the diminished sense of omnipotence, and the sense of the incompleteness of reason can be imposed by things other than disease. The environment in which the sick are cared for adds to the physical losses of illness. Beds that are too high, side rails, unnecessary wheelchair or stretcher transportation, even the bed and pajamas for people whose disease does not require the bed, all emphasize the patient's impotence and reinforce the helplessness. For the limited view of illness and the care of the sick that are provided by the concept of the sick role, we can understand the apparent utility of emphasizing the patient's helplessness. It would seem to make the job of the health personnel easier, by making the patient more compliant and more receptive to the constraints imposed by treatment. But the advantage is more apparent than real, since it only makes treatment easier, without facilitating a return to health. Since the object of treatment is to make the patient well again, the paradox in the previous sentence must be resolved.

It is clear that before one can become well from an illness, one must first become ill. Since potent psychological defenses work against an inner recognition of illness, those things in the therapeutic environment that reinforce helplessness help force the patient to accept that illness is a fact. When that has been accomplished, many things, from the acceptance of imposed pain to the taking of medication, would become easier. Indeed, in certain diseases in which no symptoms are present, such as diabetes, it may be difficult to get a patient to comply with therapy, especially if the therapy is unpleasant. In such instances, the amount of sugar in the urine can be made to cause the same lack of a sense of wholeness that physical symptoms do, and thus can substitute for symptoms. But those are examples of less common situations.

Social scientists have suggested that physicians, other caregivers, and the actual settings of medical care emphasize the helplessness of the patient, because in treatment the status and power of the caregivers are elevated. Sickness is an inevitable fact of existence, and becoming well is usually desirable. Role relationships and the functions of individuals such as physicians may organize around those essential facts, and even acquire a social configuration that almost hides their initial determinants. The paradox that the treatment situation may reinforce illness is not resolved by understanding social role conflicts, but by recourse to a simpler truth. The focus of Western scientific medicine is disease.

When doctors treat patients, they do so to get at the disease. Put another way, unfortunately too many doctors do not treat patients, they only treat diseases. Given the long history and successful development of our ideas of disease, it could be no other way.

The answer to the paradox that the environment of the care of the sick may actually potentiate or worsen some of the features of illness lies in the fact that the patient is not in the hospital or other medical setting for the treatment of illness. The patient is there so that the disease that produced the illness can be treated. *Illness* is something that affects a person; *disease* afflicts an organ. They are two distinct phenomena. A disease can be present when there is no illness at all. Hypertension is an example of a disease that may, for the greater part of its life history, result in no symptoms. It may never make its owner ill. Or, even in the absence of hypertensive symptoms, which are generally alien body sensations, the person with hypertension may become ill. Suppose, for example, that someone has high blood pressure and knows it. Suppose that both of this person's parents, who were also hypertensive, died of strokes in their middle years. Such a patient may, indeed probably will, interpret each headache or episode of tingling of the fingers, anything that suggests a weakness of a limb, as an impending stroke. The relationship between that person and the body will be altered: the sense of omnipotence will be damaged slightly. The person will be ill.

You may protest that the patient is hypochondriacal, that the illness is psychological. "Psychological," used in this fashion, usually implies that the illness is not real or that the symptoms are fancied. The hypertension is certainly real. So too are the headaches, tingling fingers, and even questions of weakness. Such transient symptoms occur in virtually everybody. One might suggest that such a person has a vivid imagination or exaggerated fears. In the face of the family history, are the fears really exaggerated? We hope that the individual will not duplicate the parents' fate, but even in this day of effective antihypertensive medication we can offer no such promise. The illness is psychological only in the sense that the mind must process all present experience in the light of past experience and preexisting conceptions. It is psychological also in the sense that without the hypertension's getting worse, the patient's fears could be reinforced by the thoughtless words of a physician ("What do you see in my eyes, Doctor?" "Well, the blood vessels are a little tortuous, show a little arteriosclerosis—the kind of thing, you know, that happens with high blood pressure.") Or, the patient's dread could be at least partly relieved by reinforcing those features of behavior, physical condition, or conceptions of the disease that demonstrate that the family history need not be a prophecy. I find it difficult to distinguish the illness as psychological or physical, but I am capable of speaking of certain manifestations of the illness as primarily physical, psychological, or even social. Since, as was noted earlier, all the features of illness can occur in the absence of any demonstrable disease, it is certainly true that the initiating event in the illness could be social or psychological. Many studies over the years have demonstrated unquestionably how frequently physical illness (appendicitis, for example) occurs during periods of life stress. It is not necessary to point out the well-known effect of the emotions on the body, but rather to make it clear that when we are considering sickness, distinctions such as social, psychological, and physical, while real in themselves, may not clarify but may confuse.

Finally, of course, disease can be the cause of, and can be associated with, the illness. Still it is possible to dissociate the manifestations of the diseased organ from those things that occur in the person as a result of the loss of function. Those manifestations of illness have been the subject of this chapter.

Recognizing the features of illness and the part they play in patients' disability makes our job clear. We are not finished until we have helped the patient to once again gain control over the environment and over self. The degree to which physicians can accomplish this will depend upon the disease, the life situation, and the nature of the patient. But the goal is clear. Details of rehabilitation cannot be left to the physiotherapy department, and are not complete when the patient can step up onto a curb. The task is more global, but the tools are readily available. In this discussion of the factors that make up illness, I have tried to provide an understanding of the places where interventions are possible. The primary agency by which control is returned to the patient is the doctor-patient relationship, which includes the actions and words of the physician who is utilizing that relationship. Skill and experience are required here as in every other aspect of medicine, but the results make the effort worthwile.

The report on postcardiac surgery recovery with which I opened this chapter detailed improvement in the patients' hearts, but not in patients. Attention to the features of illness and to the job of helping patients regain control over their lives will finish the doctor's job. Then the patients, and not just their hearts, will be better.

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