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Chapter 30

The Physician and the Dying Patient

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EDITORS' INTRODUCTION

What is it like to be dying and to have a detached individual as one's physician—how would this differ from dying when one has an empathic physician? How much does it help if the physician has come to grips with his or her mortality, and can deal with death rather than avoid thinking about it? Does it always help to be told all the truth? How important is it to be able to rely on the presence and support of one's physician? These issues are important for many dying patients. In this chapter, an internist and teacher who confronts this challenge takes the reader with him as he ministers to a dying patient.

Most physicians have three types of experiences with death and dying. The first is the direct involvement with dying patients. The second is the physician's involvement with the loss of parents, family members, and friends. This more personal and disruptive experience is only rarely without pain. The ability of the physician to be more simply human than professional in response to personal loss encourages the work of mourning to reach a successful conclusion. Often, however, the physician struggles to maintain a more detached and "objective" position and, in so doing, not only postpones or circumvents personal mourning, but makes it most difficult for other survivors either to be "with" the physician in his or her pain or to

mourn appropriately themselves. The physician's unmourned losses may lead to such excessive distancing from death as to make the physician unavailable for the kind of sensitive involvement with dying patients outlined in this chapter.

A third type of experience with death is at a different level, and involves the expectations, fears, and fantasies of the physician's own death. Such concerns are often submerged, but ubiquitous. Awareness of one's finitude, coupled with the thoughtful individual's concern about the meaning of one's life, can lead to concern, anxiety, or despair. When this pain is avoided totally by the denial of personal death, the physician is more apt to respond to dying patients with detachment and distancing.

The challenge to the physician presented by this chapter is one of both maturity and wisdom. Perhaps some readers will react, as we did in reading it, with the hope that, as that final life chapter is experienced personally, there will be available to them the kind of physician-guide presented in the following pages.

INTRODUCTION

I am going to illustrate the care of the dying by following one patient from my first visit with her until her death. The details are drawn from her hospital chart and from my office records, and most of the dialogue comes verbatim from tape recordings of our visits. Try to imagine that we are seeing and discussing this woman together, through the course of her illness.

Sally Gordon is a sprightly, pleasant-appearing woman with light brown hair and a sparkle on her face that goes with her wry humor. Smooth skin and the suggestion of a double chin (she is somewhat plump—especially for her short stature) make you think she is younger than her 62 years. Her daughter or one of her sisters is almost always with her, and the bedside table has pictures of her grandchildren and other family objects.

The surgeon asked me to see Sally Gordon the second time she came to our hospital, in April 1975. She was admitted because of persistent back pain that had raised the possibility of metastatic cancer. In August 1974, when she had been 61, she had had vaginal bleeding, and after 10 days she had visited her gynecologist. He had found a pelvic mass that had not been felt by him 6 months earlier, and advised hospitalization. Mrs. Gordon said he told her, "I feel something there and I don't know just where it is, and you're in trouble." She had asked him whether it meant a hysterectomy, and she remembers him saying, "It's a lot more than that."

Originally from Boston, she was living in Alabama, where her husband, a highly specialized electronics engineer, was working. She preferred to come to a hospital in New York, where most of her family lived.

Examination under anesthesia confirmed the pelvic mass. Preoperative studies revealed no evidence of metastatic disease, although the barium enema showed a constricting lesion at the junction of the sigmoid and descending colon. At operation in September 1974, she was found to have adenocarcinoma of the

colon extending into the serosal fat and metastatic to several mesenteric lymph nodes and the right ovary. A segmental sigmoid resection and bilateral salpingo-oophorectomy were done. The left ovary was not involved.

Postoperatively, she developed a right serosanguinous pleural effusion, at first thought to be from pulmonary infarction, but later believed to be a malignant infusion because a preoperative chest x-ray revealed a small effusion and ascites showed in the preoperative sonogram.

Before operation, the surgeon explained to her that she might require a temporary colostomy, which she dreaded. It was her understanding that "the tumor ate a hole in part of the colon and was working itself away from the colon." After surgery, she said she was relieved because, although "of course, it was malignant, they got everything, and all the radiologists and everybody said there was no concern for treatment and everything was fine. So that was that."

The surgeon was explicit to the family about her extremely poor prognosis.

She went home in 10 days, feeling fine and optimistic about her future. She was pleased about her weight loss (keeping her weight down had always been a problem), and pleased that her bowels were moving. She said later that she had "almost a phobia about bowel movements, something I never even thought about before. I interpreted somewhere that the movements were very important—after all, it was colon surgery." Her preoccupation with her bowels continued until her death in June 1977.

She came back to New York in April 1975 for a 6-month follow-up. There had been a 5-pound weight gain, which worried her because "Why should I gain weight when I'm eating so little, although I'm delighted to have so little appetite." The surgeon showed no concern, and told her how well she looked.

While she was in New York she decided to see an orthopedist about her back pain, which had been present for many years. The many other physicians who had seen her about her back always told her it was "nothing" or "a little arthritis," but it was a nagging concern to her. The orthopedist she consulted in New York found ascites during his examination and suggested a bone scan, thus raising for her the specter of recurrent cancer, and she was readmitted to the hospital.

The surgeon asked me to see her, rather than an oncologist, because I had cared for many patients who were dying of malignancy, and had become interested in the problem of the dying patient. In the surgeon's mind, in mine (and probably, in yours), she was already in the category "dying patient."

DEFINITION OF A DYING PATIENT

Why? She was not literally about to die. She did not think she was dying, nor did her husband. Indeed, she felt fine (except for her back). On the other hand, as every physician knows, she was going to die of her cancer no matter what was done. The dictionary definition "at the point of death" is certainly not how doctors use the word *dying*. A resident once said that a dying patient is someone for whom medical science has no more to offer. And a surgeon told me that "a dying patient is a patient whom I can't help." Those definitions are important to us

because they describe the state of mind of the physician who sees a patient like Mrs. Gordon. That state of mind can be induced by a pathology report ("metastatic carcinoma to lymph node") or by a chest x-ray showing a large carcinoma of the lung. But, conversely, that mindset may not follow the diagnosis "Stage I Hodgkin's disease," whereas a few years back it would have. Malignancies are not the only diseases that elicit that reaction, because so will "multiple sclerosis" or almost any disease where we feel helpless. The point is the feeling of helplessness, not the fact behind the feeling. For example, when a patient is admitted to a coronary care unit with a heart attack and shock or congestive heart failure, doctors do not usually act or speak as though the person is "a dying patient." There is much they can do, and because of that they do not feel helpless.

The first point about the care of the dying, then, is that the definition of a dying patient is not at all precise.¹ It is not like other definitions of disease in medicine, but is based on the doctor's feelings—and the predominant feeling is, I believe, helplessness. For physicians (and for everybody else) feeling helpless is very uncomfortable. Because of that, the doctor who cares for the dying must deal not only with the patient but with personal feelings of helplessness. If you think your job is the cure, or even the care of disease, then you have nothing to offer the dying patient, for by definition your tools (and thus yourself, because we so often confuse ourselves with our tools) have failed. But if you believe your job is the care of the sick, then the dying patient represents a difficult and often painful challenge, but one that should not often make you feel helpless.

TOOLS FOR THE CARE OF THE DYING

The tools that are available in the care of patients with fatal illness are the same as elsewhere in medicine: diagnostic studies, drugs, technology and surgery for the control of symptoms and disease processes, command of support personnel and ancillary services, but above all, knowledge. Our knowledge is of several kinds: knowledge of the natural history of disease and of pathophysiology, knowledge of the psychology of illness, knowledge about the behavior of patients and their families, and knowledge about ourselves. Physicians do not usually include knowledge of the psychology of illness, the behavior of patients and their families, and knowledge of themselves in the list of their therapeutic tools, because they forget that they themselves are the primary agent in the care of the sick. Surgeons know how important is their judgment and the skill of their hands, and psychiatrists understand that it is they and their relationship with the patient that makes their knowledge work for the patient, but the rest of us have seemingly forgotten that. Antimicrobials are used for infection and antiarrhythmics for cardiac arrhythmia, but it is you, the physician who is using those drugs and working with your patient, who makes the patient better.

The second basic point about the care of the dying, then, is that it is physicians themselves, including their relationships with their patients, who are the primary agents of treatment. All the tools listed above are just that—tools in the service of the agent, or of the doctor and doctor-patient relationship. If learning

to use yourself and the doctor-patient relationship consciously in the care of the dying is difficult, I promise you that it will increase your skill in the care of every other category of patient.

I suppose it is necessary to point out the difference between what I am speaking about and "hand holding" or "bedside manner." A hand holder is a doctor who sympathetically responds to patients' every whim, even while knowing that harm may be done to the patient—harm by not refusing some desire. Good doctor-patient relations can easily withstand the fact that sometimes pain, suffering, or even the painful truth are necessary for a long-term goal. Bedside manner is charm, and charm alone does not make patients better. On the other hand, neither does anticharm—the attitude of doctors who go out of their way to be gruff and tough so as not to seem soft. Optimally, then, everything that is done with the patient and the family is directed not only toward the patient's good, but also toward strengthening the doctor's relationship with the patient.^{2,3,4}

Let us go back to Sally Gordon. (I usually ask patients, male or female, whether I can use their first name, because I am more comfortable that way. Other physicians are more comfortable always using last names. What is most comfortable for you and the patient is best.) As I said earlier, back pain precipitated the admission. Although I had reviewed the chart of the previous admission and had been briefed well by her surgeon, I listened and questioned her to get the story of the entire illness from her. Doing that not only gave me a review of the case, but told me what she considered important, both good and bad. Sometimes patients will ask, "Don't you have it in the records?" I say that I want to hear the story from *them*. In fact I do, but that also says that it is the person who is my interest, not just the disease or the record.

From her recitation, I learned that her back pain had gotten much worse after the orthopedist had pointed out the ascites and requested the bone scan. Although pain had been present for many years ("The doctors say my back is older than I am."), she had begun to connect back pain with the malignancy. I asked, "Had you had pain as bad as that in the past?" She said, "Just before the bleeding episode—not just before, about May [she bled in August], and it subsided after the surgery. I was hoping, foolishly, that that would take care of my back."

It is very common, once serious disease has been diagnosed, for patients to interpret everything that happens in the light of their illness. Even though the back pain had been around for years, it was now being connected, in her mind, to the malignancy. As you will see, the back pain, which was now connected by her to cancer (although the two are not related in this instance), was to be the key to establishing my relationship with Mrs. Gordon on a firm basis.

See also how she had begun to worry about her bowel movements. At this point I suspect, but do not know, that she is afraid of local recurrence and bowel obstruction because of the "dreaded colostomy." Later I discovered that her brother-in-law was dying of bowel cancer, and that it was his colostomy and her perception of his "awful state" that provided the spectre of her worries. Often we brush aside such fears as unrealistic, but we should not because they almost

always have a basis in the patient's memories or associations. Thus even when we reassure someone because a worry is unfounded, we must keep the worry and its source in mind because it will probably return again. Worries are not random things; they are connected to one another and to what patients believe about the body, about causes of disease, and about what will happen to them. These fears often distort the sick person's perception of events and reporting of symptoms, and therefore our care. For optimum care in general, and especially with the dying, we need every clue and every bit of help we can get in managing the patient. With the dying, because there is often so little leverage against the disease, we must work as effectively as possible with the patient. For that we need to know all we can about the person. To understand the source of worries like Mrs. Gordon's, one has only to ask, "Why are you afraid of a colostomy? Do you know somebody who has had one?"

History also revealed some exertional dyspnea in the week or two prior to admission, which she dismissed as "nerves." When I was finished taking the history she said, "Of course, I'm terribly frightened and terribly nervous." I asked, "What are you frightened about?" She said, "Well, that it might be something serious." "Like what?" I questioned. She said, "Like an obstruction, or like another tumor, or like a malignancy." I replied, "Okay, then I guess we had better address ourselves to those things and make sure what is going on, so we know what to do and how to go about it."

The issue of truth telling had come up at a time when I was not ready to talk specifics. Discussions about what to tell the patient often neglect to point out that medical care is a process that takes place over time, and that patients ask questions or probe all through their care. Notice that I did not dismiss her concern or offer vague "reassurances" like "I'm sure everything will be okay." Rather, her worry was acknowledged and I declared my intent to go after the answers. By using "we," I suggested that we had mutual interests—she and I were becoming a "we" in her care.

Physical examination (in the presence of her daughter, which she seemed to wish) showed evidence of fluid in the right chest and obvious ascites. Also present was mottled red-brown skin on the right midback, the sign of overuse of a heating pad. There was a rash attributed to codeine allergy.

During the physical examination she said, "I'm awfully hard on myself. I always have been—I kind of whip myself. I've had a couple of nervous breakdowns, like." ("Crying, not eating," but no hospitalizations, and occurring at times of family stress.) I asked, "So far, how have you done, knowing that you had a cancer, being operated on, and all that?" "Great," she replied, "but this time I'm not as good as last time." "Why?" I asked. She said, "Because I have all those things to worry about that almost happened last time." "Like what?" I questioned. "Malignancy and going for tests and things like that and all those bad results," she replied.

The history and physical were over. I had obtained the story of her disease and its course, some idea of her background and her family (important to her consideration of the pleural effusion was her father's death from lung cancer),

and some concept of what kind of a person she was. In addition, I knew what she had been told about her disease. It came up spontaneously, but if necessary I would have asked, "Can you tell me what your understanding of your disease is?" or "What have the other doctors told you about your illness?"

Such information will tell to what extent denial is operating, whether the patient has been told lies in the past, and is or is not aware of that. In addition, the depth of the patient's medical knowledge is made clear, so that I do not underestimate or overestimate her knowledge, or get out of step with the other physicians or care takers. All these facts enter into the decision about what and how she should be told.

GOALS OF TREATMENT

All this information is necessary to establish the goals of treatment.^{4,5,6} In the care of patients with fatal illness, determining short- and long-term goals is as vital as in every other illness or treatment situation. Death is inevitable, but here, as elsewhere in medical care, the overriding goal is that the patient and physician remain as much in command of the situation as fate allows. Neither the patient nor the doctor should have the feeling that the disease is dragging them around the way a cat worries a cornered mouse, for that is the feeling of helplessness and loss of control. In the patient, such feelings lead to depression, despair, and suffering. Patients in that state can be almost unmanageable, and often will not do the simplest things to help themselves. A doctor who feels helpless and out of control generally avoids the patient and the situation that promote those feelings, which, though understandable, simply makes things worse.

To repeat: the overriding goal of treatment is to give patients a sense of control over their fate. It does not matter how short or restricted life may be. In the treatment process, the physician is the patient's agent. The other goals to be discussed are in the service of the primary aim of control. A patient should die the person he or she is. The subsidiary goals are (1) the control of the disease or disease manifestations to the extent feasible—not necessarily to prolong life, but to improve comfort or function, or to determine mode or place of death; (2) the control of symptoms, and teaching the patient how to manage symptoms; (3) when possible, to smooth and ease relations with other family members so that the family is able to deal better with the dying patient before death, as well as with their own feelings after the death; and (4) to achieve the best possible prognostication. This does not necessarily mean predicting the length of survival, which is often incorrect, but it does mean attempting to predict what symptoms will occur, their timing, and their response to treatment. Uncertainty in these matters is well known, but it should be remembered that no matter how uncertain the physician is, patients are more so—and it is their needs that are being met.

Often the first thing to do is to conduct studies that determine the extent of the disease. The care of terminal patients requires as much knowledge of disease and disease processes as the care of other patients. Knowing just where we stand prepares us best to meet all our goals. However, the choice of diagnostic studies

and procedures should be only in the service of the goals described above. The best test of necessity for any procedure is whether the outcome will alter action, or alter what is told to the patient. In addition, the timing of procedures should take into account the patient's fears and concerns. Things are rarely so urgent for the patient with a fatal disease.

An extensive disease workup was carried out over the next 2 days with Mrs. Gordon. It included bone and liver scans, chest films, and blood studies. She refused a projected barium enema. On my next visit, I found almost a different person. Initially, although self-described as nervous, she was in command of herself, listened, and gave thoughtful answers to questions; she had an almost sprightly, but definitely self-determined, air. Now I found her to be groaning, "whiney," almost aggressively pitiful. Such patients have a quality that would frustrate a saint. It says, "Help me—but I know you cannot." What had brought about the change was fear. In the course of the tests and the paracentesis, her fear of malignancy and disability had been reawakened. Fear could have been enlarged by the fact of the test themselves, or even by someone's thoughtless comment. Such things often happen, and are beyond our control, although we must deal with the consequences. Fear is never made to go away by telling the patient not to be afraid, or "don't worry." Fear is controlled by exposing it and relieving it at its source. Sometimes that is as simple as correcting misinformation. One of my patients, who was not frightened about his metastatic disease to the liver, became very fearful that he had "cancer of the lymph nodes." A physician examining him had spent an inordinate time searching for cervical lymph nodes, and had then called a colleague to check something. Both left the bedside without a word to the patient, except that they had been "looking for lymph nodes."

In this instance, the back pain was the focus of Mrs. Gordon's distress and groaning. I knew that to return control to her, to establish the fact that she could be in control of pain, and to show her that I was going to help her, I would have to relieve the pain. It is not uncommon to find patients in that pitiful state when they have cancer or other diseases that they believe to be fatal. They whine or groan or just lie apathetically. On other occasions, they are abusive to their family or to the staff. Whatever the behavior, it generally alienates the nurses and doctors; that makes the patient feel not only more helpless, but also abandoned. Almost invariably, there is one symptom on which the distress is focused. While anything may be considered intolerable—from impacted feces to dyspnea—pain is most commonly the key. Characteristically, the patient is suffering not merely the pain or dyspnea of the moment, but sees him- or herself as having to live that way forever—as never being free from the pain. That may also annoy and distance the physician, because the objective findings may not seem to warrant the suffering.

I started to discuss pain medications with Mrs. Gordon. As is characteristic of patients in this state, nothing would satisfy her. Codeine gave her a rash; propoxyphene was too weak; Percodan made her dizzy; meperidine was too strong; she was afraid of morphine. My dominant feelings became frustration and anger at trying to help out, but being told I was helpless. She said, "Maybe taking out

the liquid [she had had a diagnostic paracentesis] did it, but if anything, don't you think it would relieve it a little?" I replied, "It has nothing to do with it. Your back is your back—you've had that back for 15 years. Your back is not cancer. Your back is not fluid. Your back is not any one of those things. Your back is not dying." She said, "But what is it? It's incapacitating me and my life and my husband and everything." I said that we had better solve it, and she said, "Yeah, but there may not be any solution. It's taking me over."

The back pain was the key. I found a trigger point* in the right infraspinatus, injected it with 10 ml of 2 percent xylocaine, and relieved the pain. I also gave her 50 mg meperidine and 25 mg IM chlorpromazine at the same time. I chose the small dose of meperidine because she was afraid of being "out of this world." If it had been insufficient, I would have increased the meperidine with every 3-hourly dose until pain control had been achieved. Had she not expressed fear of being too groggy, I would have started with 100 mg of meperidine. The order was written "every 3 hours unless patient refuses," rather than as needed (p.r.n.), because I did not want the patient to remain in pain or be at the mercy of a nurse who felt that the patient should avoid narcotics. The usual constraints on analgesics, narcotic or otherwise, have no place in the care of the dying patient. She received only two doses that day, and two the next day, and required none further. She refused the chlorpromazine after the first dose, because she felt it made her too sleepy. By the third day, the pain of 15 years was gone, and never returned in a meaningful way through the remainder of her illness.

How had that happened? For 15 years she had been told by physicians and her family that the pain was "arthritis" or "nerves." While emotional tension may produce pain (generally muscular), pain is not emotional. Pain is pain, and the physical source can generally be found and the symptom treated. If it has been present long enough, it will produce alteration in gait, habitus, or habits that help perpetuate the pain. But, if the patient is willing, a source of intervention can usually be found through careful questioning and physical examination. Too many of us have been so thoroughly trained to treat diseases, not symptoms, that we never learn how to treat symptoms. Yet most of our patients do not have "real diseases"; they have symptoms. In the dying patient, whose disease cannot be cured, successful management demands symptom relief.

Several things had been accomplished with Mrs. Gordon. I said I would help her, and I did; the basis for my relationship with her had been established. The doctor-patient relationship is complex, but trust is the cornerstone. Patients generally enter the relationship expecting to trust. There are instances where, because of previous experiences in life or with physicians, the patient is unable to trust. The job is very much more difficult then, because unless some element of trust can be developed, almost none of the goals I am describing can be met. The best way to encourage trust is to show that you care and will come through on a promise. The obverse is not to promise what you cannot do. But if the promises are kept small and honest enough—even a night's sleep for someone who has not slept, or the delay of a dreaded procedure—patients will begin to believe that you, the physician, care about them, are dependable, and are in control of the situa-

tion. I dwell on this because the patient's wants are often trivially simple from a technical standpoint, and yet are vital to him or her. Those who have not been seriously ill may not appreciate what even mild distress over a long period can mean, and what profound gratitude can follow relief. Furthermore, the symptom, as in this instance, may have nothing to do with the disease. What counts is not only what the doctor believes necessary, but what the patient thinks is important.

Diagnostic studies of Mrs. Gordon revealed a right pleural effusion, ascites, abnormal liver scan, normal liver chemistries, and normal bone scan. Barium enema, when she felt ready for it, was normal. Cytology of the ascites showed no malignant cells. A thoracentesis removed 2 liters of fluid, also with negative cytology. The normal findings were reported to her and to her husband. Her self-control had returned, and she was again the person I first met. She still had doubts about her back pain (how could she not—it had been present on and off for so long), but she could not dispute that, between the infiltration of xylocaine and the analgesics, the pain had been controlled. After discussing the negative findings, I said, "It is possible that fluid may reaccumulate in your chest and/or abdomen, even though we did not definitely tie it to the cancer. The question has not been resolved. There are ways of keeping the fluid from reaccumulating, and we are going to have Dr. Faber [an oncologist] come to see you to help make a decision about the best way to approach this." She said, "I hope it is not going to be surgery." The fear of surgery, and notably of a colostomy, reemerged. I could honestly reply, "No, it's not." There was further discussion about how thoracentesis could be managed as an outpatient, and how she could learn to manage her own medications. I reiterated, "What I'm telling you is that my expectation is that your problems will not be over when you get out of this hospital—that you may accumulate fluid in your chest or belly, even without a diagnosis of cancer. Some kinds of tumors leave that effect behind them." She became anxious and said, "Is there a question of a tumor?"

"You were operated on for one, weren't you?" I said.

"No, I mean now, presently," She answered.

"No," I told her.

"Oh," she said, obviously relieved.

"But," I went on, "there is a question in your mind, and everybody else's mind, as to whether this has anything to do with the cancer you had before, isn't there?"

"Right," she said, pointing to her abdomen. "But this doesn't bother me. It worried me and it worried my husband." Some further conversation ensued, and I said again that Dr. Faber would see her.

"He's the lung man?" she asked.

"No, he's not," I replied, "he's a cancer specialist, and we need his advice." She grimaced and groaned. I said, "I'll tell you what—we'll call him a dermatologist."

"Nope, you said it, and that's what he is." She smiled.

"Hiding the word won't make it go away," I said to her. "When the word is out in the open, it's just what the word is. When the word is back there in your head, it's hell and damnation."

TRUTH TELLING

With the completion of initial studies, the findings had to be discussed with the patient and her family. The question of "truth telling," around which there has been so much controversy, had arisen.^{1,9,10,11}

Surveys of physicians' attitudes^{1,11} have shown that a small percentage never tell their patients the diagnosis and prognosis, and a larger percentage always tell their patients, but the majority of physicians indicated a flexible attitude. This largest group discussed the diagnosis as depending upon the type of patient, patient attitude, personality, and so on. Things are changing, I believe, and truth telling is becoming the dominant mode. But, as the previous conspiracy of silence often produced great harm, so, too, can the unvarnished truth.

For example, a 36-year-old attractive, divorced mother of two had an unsightly small lesion on the skin of her chest. Her physician removed it in the office, and sent it to the pathologist. The lesion was reported as benign, but the pathologist called the physician and said that there were a few cells that suggested mycosis fungoides. The physician then described the disease and its course to the woman in detail, ending with, "but we will always be able to keep you comfortable." Discussing the visit, she said, "He told me more about mycosis fungoides than I ever wanted to know." It took 2 weeks to put the matter to rest. The slides were submitted to a nationally known skin pathologist, who dismissed the lesion as trivial. In those 2 weeks, every mark on her skin was seen by the woman as a portent of a dreadful death. And every fear and fantasy was related to her life situation as the sole caretaker of two young children and as one who was at the start of a new career.

That is an example of a kind of mindless truth telling that appears to be becoming more and more prevalent. But did her physician tell her the truth? Or did he unburden himself of his own anxieties? Seemingly more the latter.

What is the truth in these matters? Is the truth that Mrs. Gordon has metastatic carcinoma from the bowel to the ovary, with evidence of continued disease activity from which she will surely die? That would seem to be a true statement. But suppose I told you of a patient who fit that description, and asked what I should do for her tomorrow? Or next week? You would surely ask for more information. The true statement about Sally Gordon contains remarkably little information on which to *act* (nor do statements like "Hodgkin's disease, stage IIA," "oat cell carcinoma of the lung," or even "congestive heart failure"). Those are diagnostic statements, but one cannot act on them without more information, such as: who is the patient, what is the duration of illness, has it been treated or untreated, and so on. Those diagnostic terms are a shorthand that unlocks a mine of information about cause, course, pathophysiology, treatment, and more—information that is changing all the time, as the physician learns more. Because we, and patients, have become so used to those shorthand symbols, we confuse them with the thing for which they stand—information.

The real issue is, how much information does the patient require? What information does the patient want, and how much information is needed in order to make the patient an effective partner in his or her care?

The world is changing. Modern medical care requires a partnership between

physician and patient. That may not have been so when treatment was exemplified by penicillin for pneumonia, because penicillin worked whether the patient cooperated or not. But in the case of chronic illness or long-term disease, patients themselves must do most of the things involved in their treatment, from taking potent medications correctly to following dietary or exercise regimens. And only an informed patient who feels like a partner in the process can be expected to participate fully.

Nowhere is that more true than in the patient with fatal disease who must do that most difficult but deeply rewarding thing: die well.

THE FUNCTION OF INFORMATION

The crucial issue to be resolved is the function of information. All animals, including humans, have a fundamental need to act. *The functions of information are to reduce uncertainty and to provide a basis for action.* The two functions are inextricably related. When this is understood, knowing what and how to inform patients becomes, if not easy, then easier. The basic problem faced in life is uncertainty about what to do. Moment to moment, week to week, and year after year, uncertainty exists at every turn. Wherever uncertainty exists, it is reduced by information. There are multiple sources of information. We generally think of the environment, the world around us, as the primary information source, but it is only one, because uncertainty is not only about facts. (Is diastole clear? Is the breast mass harder?, etc.) It is also about intent; the intent of an utterance, an act, or a person. And uncertainty also exists about causes and outcomes—why did this happen to me, and what will happen next? The world around will not necessarily, perhaps not usually, supply enough information, and consequently, other sources become important. Knowledge, from whatever source, stored in memory; unconscious or repressed needs, desires, fears, or fantasies; previous beliefs about how the world (and disease) works, including causes and outcomes, are sources of information. Other people are also important sources of information, and the most reliable others are not necessarily the most knowledgeable (from the physician's point of view), but rather those whom the person believes are most like him or her, or who have the same basic interests in the matter at hand. Which is why patients will often heed the advice of a neighbor in preference to that of a physician, despite the doctor's obviously greater factual knowledge.

There is one other way in which uncertainty is reduced, which is vitally important to the relation between doctor and patient. That source is faith or trust in another person—in our situation, the physician. A few moments reflection will show that in terribly important things like serious illness, there is never quite enough information to reduce uncertainty about the right thing to do, or about the future, completely. This is particularly true since those information sources listed above may produce conflicting answers—especially when the unconscious or repressed needs, desires, fears, or fantasies have been added (this is why, despite their knowledge, when physicians are sick, they are patients). In this setting of irreducible uncertainty, faith in the certainty of the doctor helps to solve the problem.

All of us have patients whose blind faith in our performance is disturbing, since we know how fallible we are. Attempts to dissuade such patients are useless, since their faith is not based on our performance alone, but on their need. Their need often arises from great fear and distrust of their body, which is seen as a mysterious source of danger. This is true in health or in minor illness, and doubly so in serious or fatal illness. Thus, the patient's incredible trust in the doctor's knowledge and certitude is virtually his or her only source of safety in a sea of uncertainty. The danger is that the physician may come to believe the patient's view, and may start to have the same faith in personal omniscience. But another danger is that the doctor may become so uncomfortable in occupying a role that is not and cannot be true, that he or she breaks the trust simply to be rid of the burden. This kind of trust in physicians explains why a patient may become very angry with a doctor when the doctor makes an error that is small in itself and in its consequences. The anger is not so much with the physician for being fallible (which is something everybody knows), but with oneself as the patient for being so dependent upon the doctor and so fearful of the body.

The basic point is, however, that physicians cannot disown the trust of their patients without destroying their effectiveness. They can only understand it as an aspect of the doctor-patient relationship that they must learn to use.

TRUTH TELLING REVISITED

Now that we understand that information reduces uncertainty and permits action, let us look again at the problem of truth telling. Did the physician who told the woman about mycosis fungoides reduce her uncertainty? No, he increased it markedly. Did he indicate, with his information, a direction of action? No action or decision was required, but he did put in doubt all the actions in which she was presently engaged—job, new life direction, child raising, and so on. Did he increase the patient's trust in him as a physician and promote the relationship? No, he destroyed it.

The question of truth telling remains, but now in a different form. Information is one of the therapeutic tools of the physician. The amount and degree of detail, the kind, its timing and truth content must depend upon the needs of the patient, the clinical situation, and the relation between doctor and patient. But each item must meet three tests.

- 1 Will it reduce the patient's uncertainty now or in the future?
- 2 Will it improve the patient's ability to act in his or her own best interest now or in the future?
- 3 Will it improve the doctor-patient relationship, the basic therapeutic modality, now or in the future?

And in all of this, the physician must remember that he or she is but one source of information, and that the other sources are generally not known to the physician.

Before returning to test this discussion against the case of Mrs. Gordon, let me venture the opinion that an outright lie will very rarely meet the tests outlined above. But in the case of fatal disease, or its possibility, the whole truth in all the detail the physician knows, now and into the future, without reference to the patient, will almost never meet those tests.

Any discussion of what to tell patients inevitably raises the question of denial. Denial does not have a very good reputation these days. In these times, everybody is supposed to know everything, and everything must be put into words, or so it seems to me. What a pity! Denial of the unpleasant is a universal psychological mechanism that can be extremely useful. It takes about 1 week of clinical experience to see patients successfully use denial to protect themselves from painful truths that are apparently so obvious that denial should be impossible. Some of the current objections to denial are a reaction of our public against the tendency of some physicians not to communicate with their patients. But that is not the whole story. The basic problem presented by denial is that a lie is involved—telling oneself an untruth. The classic instance is that of the patient with cancer on a cancer ward who tells the visitor how lucky the patient is to be well because, after all, everybody else on the ward has cancer. We stand in awe of such a belief in the face of a constantly assaulting reality. Unfortunately, for denial to remain intact, the onlookers must also lie—the family, the nurses, the doctors, and all others who know the truth. They must all watch their words, and be discreet, both in conversation and in chart notation. With the burden goes responsibility. The use of denial by a patient means that those around must share in the responsibility of protecting from pain. I believe that it is the attempt to avoid that difficult responsibility that has played a part in causing denial to be a disvalued mode for dealing with fatal illness or death. When we hear a physician simply telling the patient the “whole truth,” we must wonder whether the doctor is not simply escaping responsibility and burdens, rather than doing something that is primarily in the interest of the patient.

Denial takes many forms: simply not hearing what has been said, avoiding all conversation by absence or by changing the subject, forgetting details in whole or in part, or interpreting in a benign manner what one would have believed could only have a terrible import. Even the word usage of a patient may indicate denial where the patient apparently knows the whole truth (see Chapter 3).

Such language usage by patients is very common, and because of that, it is very difficult to hear. It is an example of how partial denial can be maintained by a patient who knows the truth. Similarly, the patient may seem, like Sally Gordon, to know the whole story, yet selectively deny some features of the illness.

Since denial is a process occurring over time, patients may gradually remember what was told to them or ask for more information at a later date when they are better able to deal with it. Patients' right to deny is as basic as their right to be told the truth. The fundamental right of patients in such matters is to have their wishes respected, whether or not the doctor agrees. Understanding patients' wishes in this regard can only come about through give and take, through interaction occurring over time. For that reason, discussions should go slowly, with the

doctor eliciting questions that can then be answered, rather than merely telling the facts. If there is doubt about whether the patient really wants the answer, the doctor can supply a partial but true answer, and elicit further questions to ensure what the patient wants. It is always possible to ask the patient, "What do you mean?" It has been amply demonstrated that when a patient really asks, he or she really wants to know.

While taking a history from Sally Gordon, I learned that she knew that the original lesion had been malignant ("Of course it was malignant . . ."), but also that she had been reassured that "they got everything and all the radiologists and everybody said there was no concern for treatment and everything was fine." But, let us suppose that I had been the physician who discussed things with her after the original surgery. Could I have lied to her at that time? To do so would have required explaining a bowel resection for a pelvic mass, perhaps on the basis of "inflammation." Two things would have put the lie in jeopardy. First, the original gynecologist had said, "I feel something . . . and you're in trouble," and, when asked if it meant a hysterectomy, replied, "It's a lot more than that." Secondly, the finding at operation so surely indicated future recurrence that I would want to avoid undermining her future trust in me.

By the time findings had to be reviewed, I had learned four important facts about Mrs. Gordon that had bearing on the discussion. First, that she had handled the news about malignancy well after her surgery. But this time, she was not doing so well because of her "fears of an obstruction, or, like another tumor, or like a malignancy." Those fears of another bowel tumor had been expressed repeatedly. The meaning and source of those fears were not known to me, and are an example of information coming from another source. Second, her father had died of lung cancer. Third, her brother-in-law, who had had a colostomy because of colon cancer, was doing poorly. Such previous experience with a disease provided information that patients may bring to bear on their own illnesses, and that may contradict what the physician says unless it is confronted. Fourth, she related a history of periods of depression that were related to family crises and required psychiatric care, but not hospitalization.

This last is of particular importance. The reason most often given by physicians for not telling the truth to patients is the fear that the patient will not be able to "take it." Included is the belief that some patients may commit suicide upon hearing that they have cancer. The evidence does not support this fear.¹² While patients' previous life adjustment unquestionably has an effect on the manner with which they deal with terminal illness,^{13,14} previous emotional illness is not in itself a contraindication to imparting true information. Since information is always being transmitted, the question for the "unstable" just as for the stable individual is whether the information meets the goals described above. To protect someone from painful information in a manner that increases uncertainty and paralyzes action because it conflicts with other sources of information¹⁰ hardly supports their personality or reduces stress.

In the actual discussion with the patient, I was quite frank. I discussed the negative findings, including the (surprisingly) negative pleural and ascitic fluid

