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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.

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## 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.<sup>1</sup> 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.<sup>2,3,4</sup>

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.<sup>4,5,6</sup> 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<sup>4</sup> 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.<sup>1,9,10,11</sup>

Surveys of physicians' attitudes<sup>1-11</sup> 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.

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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.<sup>12</sup> While patients' previous life adjustment unquestionably has an effect on the manner with which they deal with terminal illness,<sup>13,14</sup> 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 information<sup>15</sup> 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

cytology. I asserted that no tumor recurrence was evident. Here the definition of tumor was hers, not mine. There was, indeed, no evidence of recurrent bowel tumor. But, as noted above, the point was important. While it may be, indeed often is, necessary to educate a patient to the meaning of a word as used by physicians, it is also necessary to remain within the patients' usage. Where a particular word is crucial to the discussion, it is essential to ensure that both physician and patient have the same understanding, which is best done by asking, "What do you mean by . . .?"

While denying the presence of recurrent tumor, I made no attempt to avoid the words "malignant" or "cancer." Nor did I hide the possible relationship of her present findings to the previous cancer. Indeed, I demonstrated that just such a fear already existed in her mind and in her husband's. Furthermore, I insisted that Dr. Faber be called a cancer specialist, because I knew that he does not conceal that fact himself. Furthermore, what I said about a word like "cancer" is true. In the open, it is just a word—unspoken, it operates as a symbol of dread.

In all this discussion, I not only told what I thought the future would bring, but discussed in detail what it would mean (in the short run) to her, and how she could be taught to manage the problem with the help of her physicians. Thus I reduced the uncertainty of the immediate future—even though unpleasant—and connected it to positive action on her part. Thus I emphasized her control.

One final word about relating information. The discussion with the patient avoided euphemisms—words like "active," "suspicious," "condition," "nasty," "mitosis," when what is meant is cancer. There are times when euphemisms are useful, but what they generally do is signal to the patient that the doctor is afraid to use the actual word, because in everyday speech euphemisms serve that function (for example, bathroom tissue). The conventions of everyday communication do not cease because serious matters are under discussion. In fact, doctors are often afraid to use such language. The doctor must learn that to tell someone he or she has cancer does not mean that the doctor gave it to them. In addition, the use of the actual word by the physician indicates that he or she is not afraid of the word and is larger than the word, and that is reassuring to patients.

The day following the frank discussion, Mrs. Gordon's spirits were excellent. Her back pain was not severe, she had been experimenting with medications, and she was finding it easier and less troublesome than she had expected. Doctors do not expect to find patients in good spirits after such conversations. The more usual instance is the following. A woman of 69 was operated on for carcinoma of the ascending colon. At surgery, extensive local and metastatic disease was present. Her husband had died of cancer a year and a half earlier, and had not been told the truth. That had been extremely distressing to her. Three days after surgery, I found her deeply distressed. At her urging, the surgeon had been truthful with her. Most of us are familiar with the scene and know its consequences. The patient wants honesty, but in its trail comes depression, long postoperative recovery, and more severe or prolonged pain than that following surgery for nonfatal disease. That sad picture is one of the reasons why physicians often try to avoid honesty.



But in that and similar instances, the truth does not reduce uncertainty or point to action, but rather the contrary. It raises questions. Will I have pain? Will I be able to take it? Will I be a burden to my son? Will I die slowly? Should I call my sister back from Ireland? And so on. *No piece of information should be imparted unless the physician is prepared to answer the questions raised by the information, and to teach the patient how to act against the consequences.* If no questions are asked by the patient when common sense or experience suggests that the information imparted should raise questions, then the doctor should elicit the questions or even suggest them, if necessary. The process of imparting information is not complete until the facts, possible consequences, and alternative actions have been specified.

Why, then, was Mrs. Gordon in better spirits after the conversation than before? Because the information *reduced* uncertainty. It did not raise it. The uncertainties already existed in her mind (and in her husband's). She was already worried. But her worries were focused on phantoms and fears arising from her imagination. Concrete reality is rarely worse than imagined fears. If you wonder what fears and uncertainties are raised by what has been told to the patient, you need only ask to find out. With experience, one finds that the same questions arise again and again.

I asked Mrs. Gordon, "Sally, what are you frightened of? What are you scared of when you're scared?"

"Well, if it's a malignancy, then I have maybe just so long to be around, and . . ." she hesitated.

"And?" I said. "Is that what you're frightened of, dying?"

"Yeah. I'd like to be around for a little while longer." Her voice was positive.

"Well, I can understand that," I said.

"And," she continued, "I also have seen people have treatment that have been miserable."

In common with many others, she was more afraid of the suffering and misery of treatment than she was of dying. But patients treated in the manner I am describing do not have the suffering and misery that worried Sally, because that suffering and misery comes more from the feeling of helplessness and hopelessness than from the treatment or the disease. I could and did offer positive reassurance on that point.

No attempt was made to conceal our uncertainty about her actual status, nor our belief that the underlying cause of recurrent serosal transudates was most probably the previous malignancy.

Toward the end of the discussion I said, "Let me tell you again—even if it turns out that you are dying, which doesn't seem to be the case now, even if that's the case, it still has to be managed, doesn't it? Even when you know you're dying, you don't just blow away. You have day by day to go, and you have to learn how to manage that."

Dr. Faber, the oncologist, agreed that, despite the negative cytology of pleural and ascitic fluid, she should be treated as someone with metastatic cancer

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from the bowel, given 5-fluorouracil 15 mg per kg intravenously for 3 days, and then continued on chronic chemotherapy every 10 days to 2 weeks.

A pneumothorax followed the thoracentesis. This did not clear, and by the fifth day the air had increased, suggesting a bronchopleural leak. A chest tube was inserted, which functioned poorly and had to be replaced. Sufficient quantities of fluid drained so that it was evident that the chest would probably refill promptly after the tube was withdrawn. Therefore 20 mg of nitrogen mustard was instilled through the tube, which was clamped for 6 hours and withdrawn the following day. Parenteral 5-fluorouracil was started. The patient tolerated all the considerable discomforts of the tube and the nitrogen mustard extremely well. Increasingly, she learned how to manage pain, what drugs to use, and how to time them. Thus, even though the experience was unpleasant, it served to reinforce how much control she had over her situation, and how competent she could be. Each event that occurs can be used by the doctor to make the same point. If nausea or vomiting is to be anticipated, then the patient is instructed in the control of them. In each instance, the patient's trust in the physician's reliability and prognostic accuracy is increased. Since the doctor is predicting small and short-run events that are usually quite familiar to him or her, the chance of accuracy is considerable. Where uncertainty is present or alternative possibilities exist, these too should be mentioned. Doing this calls on a phenomenon known to Hippocrates. To the patient, accurate prognostication of even unpleasant events shows the physician's mastery of events and disease almost to the same degree as the ability to cure. It is in the nature of the doctor-patient relationship that when the doctor is in control, so is the patient.

#### DEFINITIVE THERAPY IN TERMINAL ILLNESS

This phase of her illness brings up the question of definitive therapies in the patient with fatal disease or terminal illness. Here, as elsewhere in medical practice, one chooses therapies to achieve a set goal. I do not like to do things whose aim is solely "to do something," although occasionally, because of family or other pressures, that becomes necessary. With Mrs. Gordon, chronic chemotherapy was chosen because it occasionally slows the progress of disease, and its mode of administration and side effects usually do not create other problems. For advanced disease with widespread metastases and terminal illness, it would have had no advantage. On the contrary, even minimal slowing of the disease process might prolong the patient's dying and distress, although I will discuss that in greater detail later.

The nitrogen mustard offered a chance of stopping recurrent pleural effusion, and is an example of a treatment aimed at a specific symptom or manifestation that in itself causes major problems. Dyspnea is a difficult symptom to manage, since the fear of choking to death that it evokes is so primitive. Patients can be taught, with difficulty, how to avoid the almost automatic body responses (such as the "asthma position" of shoulders up and forward, with hands on knees), which increase anxiety and increase the severity of the symptom. Mor-

phine, in small doses, is also useful, and can be easily self-administered subcutaneously. Oxygen in the home also provides comfort. Whatever reduces the anxiety also reduces the severity of the symptom. Where repeated thoracenteses become necessary, considerable ingenuity may be required to make them innocuous. Although they are to be avoided, problems of infection are of less importance than in patients with benign disease.

Persistent bleeding from the bowel or incipient intestinal obstruction may be reasons for bowel resection even in the face of metastatic disease. With these decisions the physician is, in essence, choosing one mode of death over another. Such choices must take into account many variables, from the suspected time of survival (usually longer than one thinks) to patients' fears—of surgery, costs, home situations—specific desires, and so on. Those many factors, which are almost always present in serious illness, are perhaps nowhere more important than in fatal illness.

Since the primary goal is to maintain maximum function and freedom from interference by the disease and by medical care, and to keep the patient in as much control of his or her circumstances as possible, some disease manifestations are more to be avoided than others. Metastatic disease to the spine, aside from causing pain, may lead to cord compressions and subsequent paraplegia. Thus, radiation therapy is often indicated, even if prospective survival time is quite short. Disease progression at such sites may be very rapid. Thus, alertness to any symptom indicative of spinal disease or neurological involvement is necessary. Other areas of bony involvement may also produce pain or predispose to pathologic fracture, and can often be radiated with benefit. Radiation to the upper lumbar spine will usually be accompanied by nausea, against which the patient should be forewarned and forearmed with enough medication and detailed instructions for its use. Antiemetics given before the nausea is expected are more effective than medication started after nausea or vomiting has started.

Alertness to symptoms poses a problem. Early in the course of the illness, patients may interpret any symptom, however remote or commonplace, as a sign of the return or progression of the disease—remember how Mrs. Gordon connected her long-standing back pain to her malignancy. Much of the physician's time with the patient will be spent in providing reassurance. Nonetheless, one wants to know what symptoms are present, and the interest of the doctor always gives a symptom more importance to the patient. Patients in bad situations, indeed all of us, always give the worst interpretation to every word or clue; therefore the physician may have to say specifically why certain questions have been asked. We do not want patients to feel that their lives are literally hanging on our words, or connected to a chest x-ray or blood count, for that is a terrible state. We are trying to focus on living, not merely by lectures, but by providing the tools to keep their illness at a minimum. Sometimes that can be very difficult. For example, a single woman in her forties had a mastectomy for comedo carcinoma. Within 2 years, she had developed asymptomatic pulmonary metastases. The nodules melted away after bilateral oophorectomy. (She asked, "Why do they call it castration when ovaries are taken out for this reason, but

oophorectomy when done for other reasons?"—a good question.) During all this time she was well and functioning and her career burgeoned, but she was overwhelmed by fears. After each chest x-ray, she would break into tears when told it was negative. She always wanted to know "her percentages" (something I avoid), and even called the American Cancer Society to find the average length of remission after oophorectomy. Each visit to my office was agony. Two years after the oophorectomy, she was apparently free of disease. Meeting her surgeon, I told him how well she was doing. "Is she enjoying these extra years of life," he asked, "or are they more years of dying?" "More years of dying, I'm sad to say," I replied. I could not seem to teach her what I am describing in this chapter. But then something happened. The oncologist who had been our consultant, and for whom we all had affection and admiration, died suddenly of myocardial infarction. His death was sad to me, but it was to her the lesson that finally made the point that death may happen to anyone; it is living that counts. The pulmonary nodules returned about 6 months later, and she handled it well. She took an active part in the choice of appropriate therapy, and sought advice carefully. She has now been on calusterone for about 3 years, and is apparently free of disease. Her body fears are not gone, but the added years are years of life.

One is always balancing the benefit of diagnostic studies, doctors' visits, questions, and so forth, against the goals. Flexibility is the key.

#### PSYCHIATRIC ILLNESS IN FATAL DISEASE

Mrs. Gordon went home to Alabama and to her previous life. She did well, and had no difficulty with the chronic 5-fluorouracil. Psychiatric symptoms arose that were similar to those she had experienced in previous years. She consulted a psychiatrist near her home, who felt that she had every good reason to be depressed. She was, after all, dying. Her family physician and others shared that opinion. I did not. While depression may be common in patients with fatal disease, it is by no means inevitable. There has been considerable discussion about depression in the dying patient,<sup>13,14,15</sup> but it is important to distinguish symptoms that are a necessary part of the illness from those that come from its treatment. We believed previously that prolonged fatigability was a necessary sequela of myocardial infarction. It ceased to be common when patients were no longer maintained at bedrest for many weeks. Sadness, unhappiness, anger, or other emotions may all occupy the patient from time to time, as they do the rest of us. Depression may also be present, but in patients who have been treated in the manner I am describing, it is usually brief. When present, it is generally proximate to the original illness, to a recurrence, or to a particularly difficult aspect of the disease.

Why should Mrs. Gordon have become depressed when she did? She was functioning well and aside from poor appetite (which she liked), she was essentially free of symptoms. It appeared more likely that her depression was associated with emotional problems that were either unrelated to or only peripherally related to her malignancy. That turned out to be the case when she



successfully sought other psychiatric care. The error is to see the dying patient as so totally occupied in the dying process that no other emotional stresses seem pertinent. Mrs. Gordon's depression was due to the same kind of emotional material that had precipitated it in years past when she did not have cancer. The patient with fatal disease, even when that disease is terminal, has as much right to relief of emotional pain as any other person, and much has been written on the subject.<sup>14,19</sup> Furthermore, the usual rules of privacy and confidentiality should be observed with dying patients as with others.<sup>1</sup>

Psychotropic agents such as the tricyclic antidepressants can improve these patients profoundly, just as phenothiazines or minor tranquilizers may help control anxiety.<sup>2,17,20</sup> However, one should be careful when using minor tranquilizers like the benzodiazepams, meprobamate, or barbiturates, which have a sedative effect. Sometimes the patient's anxiety or agitation comes from the physical confinement of the illness, if this was a previously active person. The sedatives slow the patient's activity further, and that slowing may increase depression, agitation, or anxiety. In such instances phenothiazines are better.

### THE FAMILY

The family of the patient may also require considerable help in adjusting to the coming death. When one family member is seriously ill, family dynamics change.<sup>21</sup> Relationships may be so disrupted that the family unit does not recover, whether the sick person lives or dies. On occasion, long-standing conflicts disappear, and everyone seems closer and happier. During remissions the old battles can reemerge in those families, but because of the preceding peace the battles now seem worse than ever. The basic point is that when there is sickness in one member of the family, the family unit itself may become sick, and you may have to give thought to the others. All the psychological mechanisms that appear in the patient, from denial to anger, occur in the family and are frequently directed at the physician. Anger and suspiciousness can be difficult to deal with. The family sometimes views the doctor, hospital, nurses, or anybody caring for the relative as "them," the enemy from which the patient must be protected. They question every medication and decision. If the doctor is extremely open, they seize with hostility any expression of doubt or indecision. If the doctor is closed to them, they bombard him or her with unanswerable questions. Frequently, such families will play one physician against another, thereby placing considerable strain on staff relationships. Such behavior tends to personify all injury. If family members feel pain or distress, it is because some person has done it to them. The hurt and sadness of the impending death are often not seen for what they are, the reaction to the loss of a loved one, but rather what others are doing to them directly. The physician is the prime target. And they may use every wrong act of every physician all the way back to Hippocrates as current evidence—injury is timeless. In these situations, which fortunately are not common, I am extremely uncomfortable. When anger alone is the emotion, it has sometimes helped to point out that it is easier to be angry with me than with the real enemy, fate or

disease. But in the face of the whole battery of anger and suspiciousness, interpretation is rarely useful. When that happens, then I must try doubly hard to remain open to the patient, who rarely shares in the behavior. In these litigious times, there is no question that such family actions can impair the quality of care that the patient receives. It helps, however, to keep one's eyes focused on the patient and the patient alone.

In the more usual instance, even though the sick person remains my primary responsibility, I try to meet family needs also. Direct conflict most often appears at the point of truth telling. The family may say that the patient "can't take it." But it is often not clear who cannot take what, and it is necessary to make delicate inquiries to find out where the problem lies. I try to explain to the family what my goals are, how information functions, and how I handle telling the patient. If conflict remains, I do what I think best for the patient.

On one occasion, the family flatly and adamantly refused permission for me to tell the sick mother what her state was. I went along with their wishes. Her disease, metastatic tumor to the brain, progressed and the patient, who appeared to know very well that she was dying, became more depressed. She was discharged from the hospital after radiation therapy, but returned a month or so later with acute bacterial pneumonia. Without the pneumonia she did not have many weeks to live, and this acute illness, untreated, would have been a kind end. Against my advice the children refused permission to leave the pneumonia untreated. The infection cleared rapidly with antibiotics. One day as I saw her on my rounds, I was struck by what a sorry sight she was. Slumped down in the bed, with I.V. tubings and the other paraphernalia of acute disease connected, with her left hand restrained because she had attempted to remove the I.V., apathetic and watching me intently, she looked like most other dying patients in the modern hospital—what my patients used to look like before I began treating them as I am describing here. I had forgotten how awful it was. What a miserable way to end a human life: as an object. As I walked out of the room depressed, one of the sons stopped me to thank me effusively for the wonderful things I had done for his mother's pneumonia. I lost my temper and told him how unnecessary I thought it was for his mother to be in that state. My anger helped no one, not me, not the son, and certainly not the patient. But I resolved never to let that happen again. If patients choose denial, that is their right, which I will cheerfully respect. But never again will I allow the family's denial to destroy the death of the patient.

Most often, however, even when they disagree initially, the family comes to see that honesty helps not only the patient, but the rest of the family also. It is inherently a bad situation, it seems to me, when the family knows something the patient does not. A conspiracy of silence develops, which may loosen family bonds at a time when closeness is most important. Perhaps the most painful situations are those in which the dying person knows the truth, but the rest of the family either thinks that the patient does not know or refuses to let the patient talk about his or her illness or fears. When that happens, to the distress of illness is added the loneliness of unburdened fears—not only fears about illness or death, but also

fears and problems concerning the children's future, the spouse's life ahead, all the details in the lives of those who will be left after the person dies. Even if the family does not wish to discuss these things with the patient, the physician can do so by making it clear to the patient that he or she is available for open and direct conversation.

It is best when the family takes the opportunity of open knowledge to bring things to closure. Those old pictures of the dying parents giving their blessings and final directives to the remainder of the family are not merely romantic fantasy. When patients are aware and in control of their circumstances, a calmness is present in their rooms, even with a grieving family. Leavetaking becomes a desirable possibility. It may be necessary and useful to have other staff members work with the family. Social workers are increasingly skilled in working both with dying patients and with their families. In some institutions, a team approach has been successful for handling these problems, both before and after the death.<sup>6,22</sup>

While the emotional reactions to impending death in both patient and family can be handled by others, the dying person's doctor cannot remain aloof from them and hope to achieve the goals that I have described. No matter who else comes into the patient's room, there is usually only one identified by the patient as "my doctor." It is that relationship, I believe, that makes the goals achievable. One final word about the family. However well the terminal illness goes from the physician's point of view, the family will not be pleased at the time of death. In this respect, the care of the dying is different from returning others to better function or good health. The survivors have suffered an irremediable loss and tragedy. No parent is so old that it is "all right" when he or she dies. A mother or a father has died, and life will always be different for the survivors now. The family may be relieved that the suffering is over, but guilt seems inevitably to accompany that relief. No matter how aware the doctor is that suffering and distress were minimal, or could have been much worse, the survivors will have perceived suffering, if only because they are suffering. While the family may not appreciate what has been done at the time, they usually become aware eventually of how well things have been handled, and become grateful at the mode of death. The "death with dignity" movement of recent times has led to expectations that death can be almost beautiful, or at least dignified. That is patent nonsense, as physicians know only too well. Our desire is that patients die as much themselves and in command of their death as possible. Nothing can lessen the pain of loss. What we are trying to avoid is making the pain more. And, sadly, a life lived poorly cannot be remade on a deathbed.

#### THE TERMINAL PHASE

Mrs. Gordon visited her family in New York in the spring of 1976, about 1 year after discharge. I examined her when giving the 5-fluorouracil she still received every 2 weeks. She was cheerful and healthy-appearing, in keeping with the reports I had received. After her husband's retirement, they had moved to Florida. However, her liver was enlarged and nodular. There was no ascites. The

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extent of metastases had obviously increased. In response to her general question, I told her how well she was doing. If she had asked a direct question about her liver or its nodules (as have other patients), I would have answered equally directly. Her conversation suggested that she had chosen to deny the illness, and I saw no reason to interfere.

She remained well until March 1977, when I got a frightened telephone call that her abdomen was enlarging. Her local physician said he could find nothing. She was soon to come to New York to see her daughter and her just-born third grandchild (this daughter's first child), and I suggested she see me. Moderate ascites was present, the liver was larger, and there was tumor palpable in the old suprapubic incision. She was pessimistic about her future, and was sure "I'm just about finished." I said, "You believe that old tale, don't you? About when a grandchild is born a grandparent dies?" She nodded and said, "Well I know that happens." In our further conversation, I tried to reinforce my statement that her death was not inevitable at this time. I was attempting to reverse her mind-set that she was now dying. It was the only therapeutic tool that might still be useful. It can, within limits, be successful. No one who works with the dying can fail to be impressed by patients' occasional ability to die when they predict, or to stay alive until a predetermined event has occurred, such as a child's graduation, a birth, or a set of holidays. I was attempting to actuate the same phenomenon to restore her balance with her malignancy as I have with other patients. A similar instance is that of the patient with chronic urinary tract infection who remains well and asymptomatic until some other event, physical or emotional, changes the balance, and frank clinical illness ensues. Recovery merely means chronic asymptomatic infection again.

Mrs. Gordon's chemotherapy was advanced to every 10 days. The ascites increased, and she became uncomfortable. A simple, slow, outpatient paracentesis was done by using an intravenous polyethylene catheter. I told her that I could not know, but it was my hope that, just as in the past, the fluid would not reaccumulate. I urged her to get back to her life, and so she returned to Florida. About 1 month later, by telephone, she said that she was tiring easily, but everyone was urging her to be more active. I also urged her on. One week later her fatigability had increased, and she complained of pain in her back, which she blamed on nervousness. I asked that she and her husband come to New York, even though the trip might be difficult. It is very important that the doctor does not urge a patient to function past his or her physical capacity because the patient often takes the blame for failure. Though it is true for all, this is especially important in terminal illness, where the primary resource that has been constructed, reinforced, and depended upon is the patient's sense of being in control. Led to believe that the only reason she was not being more active was "nerves," she might lose her confidence in the control that had served her well for 2 years. On May 18, 1977, the Gordons went from the airport to the emergency room, where I met them. She was obviously ill and jaundiced. Moderate ascites was present, but a tumor mass occupied much of the lower abdomen and liver. The back pain came from a pathologic fracture of the right fourth rib in the posterior

axillary line, with a 10-cm tumor mass surrounding. It was only painful when pressed. I did not x-ray her or do other studies. The bone ends could be heard clicking on auscultation.

I explained that she was ill because of her disease, which had gotten worse. The lump on her back, I said, was from her disease. She was relieved that it was not her old back pain. She did not want to hear the word tumor. "Does that mean I'm on my way out?"

"Yes, it may mean that, but I cannot be sure that you won't start getting better again." As initially 2 years earlier she heard only the good news, now she heard only the bad. She wanted to know how long she would live. I explained that if she remained in control and "kept her cool," that she would probably die within 10 days or 2 weeks after she had finished saying goodbye to everyone. I told her that death is not the enemy, and that disease is not the enemy; the enemy is fear. Every symptom that she may have had could be controlled, except weakness. But if she did not get frightened and remained in control, she would have very little pain. I wrote prescriptions for meperidine, chlorpromazine, hydroxyzine, and propoxyphene, and explained in writing how they were to be used. Hydroxyzine is also effective in reducing the amount of analgesics necessary (25 mg or 50 mg four times daily), and usually does not produce as much sedation as chlorpromazine.

She and her husband were dismayed by what I said. Only a few weeks earlier, they said, I had told them everything was going to be fine. I pointed out that I had not said that, but did not press the point. Patients hear when and what they need to hear. Now they could hear bad news. Despite being shocked by the information, she remained calm. Before they left for their daughter's home, I cautioned again that her only real enemy was fear, and that she had done so remarkably well and handled everything so beautifully up until now that I was sure she would be able to do whatever was necessary.

#### Fear of Death

And fear is the enemy, but fear of what? It is generally assumed that dying patients are afraid of death. Some insight into the fear of death is necessary for physicians who care for the dying. How many of us are there who have not given thought to the fear of death? It fills the fantasies of children and adolescents, occupies countless midnight hours in the healthy, and infuses the contemplation of students of the human condition. People mark themselves for a lifetime on how well they have met that fear. Whole cultures and societies develop mechanisms to deny death and handle the fear of its omnipresence. Religions speak directly to the issue, and many people with a deep and abiding belief in God and the hereafter seem little afflicted by a fear of death. From all of this, we know that the fear of death is ubiquitous and that, considering the simple finality of its source, it should be understood easily. I think not, however, and some paradoxes point to its complexity. Generally speaking, the aged fear death less than the young. How odd it is that the closer one gets to death through the natural unfolding of years, the less frightening it becomes. Sir William Osler once wrote



that he could hardly remember a dying patient who was afraid of death. That too has been my experience. What studies have been done show the same thing. Avery Weisman concluded that the absence from his subjects of a fear of dying was an artifact of observation and not a true indication of lack of concern.<sup>23</sup> More recent work confirms those results, but shows that questions that elicit below-awareness responses to death-related materials are handled differently by the dying (but similarly in patients with heart disease and cancer) than they are by healthy subjects. It is concluded that such responses indicate greater fear of death.<sup>24</sup>

But concern and fear are very different, and it is an error to confuse the two. We would be very surprised if the dying had no concern about their impending death, if it did not occupy their thought.

The fear of death that most of us know is, I believe, quite different. It first appears in children so young (age 4 or 5) and so devoid of life experience as to cast doubt that the fear is of the unknown, future nonexistence, or the body's rotting in the grave. What then is the fear of death? In the child, it is the fear of nothingness, the fear of separation and disappearance, the fear of loss of object or separation from the object. All these fears have their basis in a very recent reality for the child. In adults who have a fear of death, the same mechanism is commonly the basis. We, the living, remote from our own deaths but standing at the bedside of the dying, must not confuse our own fear of death with the patient's fear of dying. To do so would be to deny dying patients a means to remain in control of their own deaths. Our fear is a luxury of the living, an abstraction of our past. The sick deal with the concrete—pain, nausea, thirst, weakness, and the fear that they will not be able to "take it," and so on. Those are the things that form the basis of the fears of the dying, and with good reason. But those are things for which we have excellent tools. Our enemies are not vague apparitions like the fear of death, but instead are well-grounded apprehensions that are common to all the ill. Doctors have done battle with symptoms like pain and nausea since the beginning of time, because those things rob patients of independence and of their ability to rise above the ever-narrowing confines of the dying body. To the extent that we work against the symptoms and teach patients how to manage them so that they can maintain control over their own deaths, we are successful in treating the illness called dying.

You might believe that when Sally Gordon heard that death would come, she would lose all hope and fall apart. But that did not happen. She remained calm and tranquil. She had things to do. She must say goodbye to her family. She and her husband were angry with me for a few days, but the anger passed. During one conversation, she related how her sister suggested she take the current quack anticancer drug, Laetrile. She said, "I told her that was just silly." Not the comment of someone who was hopeless and grasping at straws. We are always hearing that we must not take hope away from our patients by telling them of their cancer or impending deaths. Yet these patients do not seem without hope or act hopeless. Others have made the same observations.<sup>25,26</sup> Neither do old people who know that death is near act hopeless. To know that one will die, therefore, is

not the same as having no hope. On the other hand, hope is a future word, and these patients would seem to have no future. They may not have a day after tomorrow, but they have a tomorrow and they know what it contains. It is not a tomorrow of awful uncertainty, but rather of concrete realities that they have learned to surmount. These are sick people, and the sick are rooted in the concrete present. The larger future abstractions of the healthy do not concern them. Once again, the physician must not confuse personal mentation or the thoughts and dreams of the healthy with the concerns of the sick. To do so may be to deny them what they require—the control of now.

After about 10 days in New York with her sisters, daughter, son-in-law, and grandchild, she went to Atlanta, where her other daughter and family lived. I transmitted the details of her case to the physician who would be caring for her there. During her last visit, I assured her that the doctor knew about her, but that he could call me if needed. She thanked me for everything, the way patients do.

I heard from her son-in-law that after a week or so in Atlanta she began to get quite weak and had to be helped back and forth to the bathroom, which distressed her, as did some rectal bleeding that occurred. She was grateful to be admitted to the hospital. After 2 days, on June 20, 1977, she died, 2 years and 9 months after the original surgery that had shown the metastatic disease. During those 33 months, her total illness disability time, including the surgery and subsequent hospitalizations, was perhaps 2 months, of which 1 month was the terminal illness—a rather typical career for a dying patient who has been treated as I have described.

#### HOSPITAL VERSUS HOME

It has been pointed out repeatedly that in this era more patients die in institutions and fewer at home. The modern hospital, devoted as it is to the aggressive care of acute illness, is said to be a very poor place to die. That need not be the case. On the other hand, families may be grateful for the opportunity to care for the patient's terminal illness at home. Often the family would like to keep the patient at home, but feels inadequate in the face of the responsibility and what appear to be overwhelming details. Economics may dictate the choice when the patient's insurance will cover hospitalization but not care at home. Even in the absence of insurance coverage, use of community resources and agencies, such as Cancer Care or The Muscular Dystrophy Association, may make home care of the terminal illness possible. Planning is required, and the physician may have to invest considerable time in providing the necessary instruction. Adequate medications to meet almost any contingency should be provided, along with detailed instructions about their use. In this era, many laypersons are capable of handling the most sophisticated drugs, and even injectables. However, if any major barrier, emotional, language, intelligence, or other, suggests that instructions cannot be given or followed, the patient should not be cared for at home. The decision should not be based on current ideology, but rather on what is most desirable and practical.<sup>20</sup>

There is no reason why a terminal illness cannot be handled extremely well in

the hospital when the goals are understood. Only things that contribute to comfort should be done. As with Mrs. Gordon, the patient is often grateful to be hospitalized. Some things that are generally avoided, such as the Foley catheter, become objects of mercy, since they allow the patient who is in pain or is extremely weak to avoid moving. Where weakness is very distressing to the patient, it may respond to 15 or 20 mg of prednisone daily in divided doses. This is particularly true of terminal carcinoma of the lung,<sup>20</sup> where the weakness may be attributable to hypercalcemia. Discomfiting anorexia and mild nausea will often improve when the diet contains very little protein. In any case, patients should be reassured that eating is not necessary but that adequate fluid intake will make them more comfortable.

### The Relief of Pain

*There is absolutely no excuse for suffering caused by pain.* Patients in pain require analgesia. The only important criterion for choosing dose and type of drug is whether adequate relief is obtained for an adequate period of time. When an agent appears ineffective it should be changed, the dose increased, and/or the interval between doses shortened. The patient's statement is sufficient evidence that pain has not been relieved. When pain is mild, simple drugs such as codeine given orally are preferable. But where pain is severe, particularly in a patient seen for the first time, give whatever is necessary to stop the pain. Remember that you are not only trying to relieve pain, but to demonstrate to the patient that control is possible and that you can be trusted to help. Although Sally Gordon was given meperidine because she was afraid of morphine, I prefer morphine because it can be given subcutaneously and seems to provide greater comfort. The intramuscular injection of meperidine is in itself painful, and after days of use produces buttocks that look like a purple pincushion. When you do not know whether the patient will become nauseated or vomit with an analgesic, give chlorpromazine or another phenothiazine at the same time. I do not like to substitute retching or vomiting for pain. After initial pain control has been achieved, you may, in working with the patient, try other regimens, in order to produce fewer side effects while maintaining comfort. Orders written "as needed" or "p.r.n." have no place in the treatment of pain in fatal disease. I often write my orders this way:

- 1 Morphine sulfate 10 mg subcutaneously every 3 hours, unless the patient is asleep or refuses.
- 2 Codeine sulfate 30 mg p.o. every 3 hours, unless the patient is asleep or refuses.
- 3 Patient may have morphine even if he (or she) has recently had codeine.
- 4 The object is to achieve complete relief from pain.

Then I show the order to the nurses and also to the patient, so that both understand the goal. Considerable ingenuity is sometimes required to find the proper drug or combination and the proper timing, because pain patterns differ from patient to patient. Almost invariably when analgesics are given in this

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manner, the patient's need for medication will quickly diminish within 2 or 3 days. Patients may be avoiding the stronger agents because they do not like the grogginess or other side effects. Some pain may remain, but with fear gone the discomfort may be minimal. Whenever pain has been present for long periods, muscle spasm is almost invariably present, and thus hot or cold application or physical therapy may be useful. Other modalities, such as nerve block, may also be tried when necessary.<sup>27</sup> I have no experience with Brompton's mixture (oral narcotic, cocaine, and alcohol) used at St. Christopher's Hospice in London and elsewhere,<sup>28,29</sup> but I would not hesitate to use it. The basic principle is simple—do whatever is necessary to relieve pain. The success in the management of terminal illness achieved at St. Christopher's comes in part from the recognition that chronic pain is a combination of physical, psychological, and social factors for which analgesics are necessary but not sufficient. The patient must be cared for as a person whose needs, desires, opinions, and fears are respected and dealt with. The patient should never have the sense of being abandoned.

At this late stage in the illness, when death may be near, the family must be given prime consideration. People frequently want to be nearby when a loved one dies, and this should be accommodated when possible. It is misplaced kindness to spare them unhappiness by false optimism or by denying access to a deathbed. I am frequently asked whether a son or daughter should be called back from college, or whether a young child should be told. My answer is invariably yes. The preventive treatment of grief starts before death. In this and other aspects of the care of the dying, the Golden Rule is a good guide.

The physician who has been open, direct, and honest with the patient throughout a fatal illness has an important tool with which to deal with the terminal phase. His or her relationship with the patient will be good, and a strong bond based on performance will have been formed. The patient has seen that the doctors' prognostications have generally been accurate, and symptom relief and other promises have been fulfilled. It is within the power of the doctor-patient relationship for the physician to suggest to the patient that the time has come to die. We spend our lives fighting sickness, regression, disability, and death. Physicians spend their lives in the service of that fight, exhorting and abetting the will to live, the life-force. Call it what you will, measurable or not, we know that the life-force exists, and that it is potent. But there is a time to stop—not merely to stop the application of technology but to actively help the dying patient develop the will to die.

This can be done with the terminally ill in the most practical terms. It is possible to suggest to patients that the time has come to leave, but at the same time to reassure them that it is all right to leave and that it is not going to hurt. When this is explained to patients, you will discover that they become more peaceful; that pain, if present, becomes less severe and more bearable; and that within a relatively short time death follows. Since in the terminally ill what is being done is tantamount to telling the patient to die, one must have the technical and clinical evidence, as well as consultations where indicated, to support that judgment. The doctor must face the responsibility openly. He or she must be cer-

tain, in the light of medical science and of personal experience and judgment, that the time has indeed come for the patient to leave. The process is based on trust. The patient is being told that it is permissible, indeed necessary, to stop doing what has been done for a whole life—namely, battling for life—and that it will not hurt. To accept that assurance requires the deep and abiding trust of one human in another. It is not necessary to be blunt or direct, although some patients wish that. One can say "All right, you've done a good job, now just lie back and be peaceful," or "You don't have to struggle with your breathing anymore, just give way and let it happen—like sleep, it won't hurt." As the days go by, you must assure them of what a good job they are doing—and how well they have handled everything. We all deserve praise for things well done, even our dying. They have no standard for comparison, but you do, and you can point that out to the patient and the family. You may not actually ever use the word death or dying, although the word should not be avoided if the patient desires. Those last days are not the time to back away from medications. Morphine with or without chlorpromazine can reduce restlessness, and the patient's clouded consciousness is not a contraindication. Around-the-clock orders are preferable because they relieve the nurses of the burden of decision making. Predicting time of death is difficult, but the family will often want to be near so one does the best one can.<sup>29</sup> It is permissible to make it clear on the chart that the patient is not to be resuscitated, especially if that has been discussed with the family.<sup>30</sup>

The physician's ability to help the patient die comes not only from the patient's trust but from part of a doctor's function, the giving of permission. The social scientists, who have pointed out that physicians validate their patients' illnesses for society, fail to see the constant battle between self and body, between pain and will, that takes place in illness. The disease may be the cause and the social setting may be the stage, but the battle is in the person. It is the physician who gives permission for a person who becomes ill to stop and do battle for the body. And, once health has returned, it is the physician who gives permission to get on with life without fear of or for the body. In the care of the dying the physician can, based on trust and in the service of his or her patient, give permission for the person to stop the battle for life.<sup>31</sup>

Mr. Gordon came to see me early in September. He wanted to tell me about his wife's last days, and to thank me and to express his doubts about some things and clarify others. The visit only took about 20 minutes, but it was very important to him. In those situations I am always somewhat worried that the survivors will be angry with me, but that is not their purpose. They come to effect closure, and it is often several months before they are prepared to do it.

He described her last few days in detail and wondered, typically, whether it would have made any difference if he had brought her to the hospital sooner, when she did not want to go, and whether she should have gotten a blood transfusion a few hours earlier. One wants to dismiss those things as silly—death was inevitable—but should not. I listened until he was finished, and explained that those and the other details he mentioned would not have made a substantial difference. I think the survivors, who inevitably feel guilty no matter how well



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they have done, really want to ask whether all kinds of things, parts of the past and of the way lives were lived and relationships unfolded, made a difference. But survivors usually do not know or cannot say those things, so they ask about terminal details.

He thanked me for my help and for keeping her alive so long, and wanted me to thank the thoracic surgeon who had handled the chest tube so well. Out of modesty or embarrassment, one tends to brush away the thanks but should not. "Thank you" is the only meaningful gift the survivors have to offer, and it should be accepted gracefully.

He wanted to know more about her disease. I explained in complete detail how much disease and how much evidence of metastases there had been for so long. "I didn't know that," he said, "why didn't you tell me?" I replied that he had not asked, and I saw no purpose—would he have been able to do anything better or act differently if he had known? He agreed. Then he said he was not sure whether it had been correct to tell her, at the end, that she was dying. However, when they discussed it she had told him that she already knew. He left feeling much better.

The care of Mrs. Sally Gordon had ended.

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1. The first part of the paper is devoted to a general discussion of the problem of the existence of solutions of the system of equations (1) for arbitrary values of the parameters  $\alpha$  and  $\beta$ . It is shown that the system has solutions for all values of the parameters  $\alpha$  and  $\beta$  if and only if the condition  $\alpha + \beta = 1$  is satisfied. This condition is also necessary for the existence of solutions of the system (1) for arbitrary values of the parameters  $\alpha$  and  $\beta$ .

2. In the second part of the paper, the problem of the existence of solutions of the system (1) for arbitrary values of the parameters  $\alpha$  and  $\beta$  is solved. It is shown that the system has solutions for all values of the parameters  $\alpha$  and  $\beta$  if and only if the condition  $\alpha + \beta = 1$  is satisfied. This condition is also necessary for the existence of solutions of the system (1) for arbitrary values of the parameters  $\alpha$  and  $\beta$ .

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