

II

Attitudes Toward Death and Dying

Men are cruel, but Man is kind.

Tagore,
from *Stray Birds*, CCXIX

Society's Contributions to Defensiveness

UNTIL now we have looked at the individual human reaction to death and dying. If we now take a look at our society, we may want to ask ourselves what happens to man in a society bent on ignoring or avoiding death. What factors, if any, contribute to an increasing anxiety in relation to death? What happens in a changing field of medicine, where we have to ask ourselves whether medicine is to remain a humanitarian and respected profession or a new but depersonalized science in the service of prolonging life rather than diminishing human suffering? Where the medical students have a choice of dozens of lectures on RNA and DNA but less experience in the simple doctor-patient relationship that used to be the alphabet for every successful family physician? What happens in a society that puts more emphasis on IQ and class-standing than on simple matters of tact, sensitivity, perceptiveness, and good taste in the management of the suffering? In a professional society where the young medical student is admired for his research and laboratory work during the first years of medical school while he is at a loss for words when a patient asks him a simple question? If we could combine the teaching of the new scientific and technical achievements with equal emphasis on interpersonal human relationships we would indeed make progress, but not if the new knowledge is conveyed to the student at the price of less and less interpersonal contact. What is going to become of a society which puts the emphasis on numbers and masses, rather than on the

individual—where medical schools hope to enlarge their classes, where the trend is away from the teacher–student contact, which is replaced by closed–circuit television teaching, recordings, and movies, all of which can teach a greater number of students in a more depersonalized manner?

This change of focus from the individual to the masses has been more dramatic in other areas of human interaction. If we take a look at the changes that have taken place in the last decades, we can notice it everywhere. In the old days a man was able to face his enemy eye to eye. He had a fair chance in a personal encounter with a visible enemy. Now the soldier as well as the civilian has to anticipate weapons of mass destruction which offer no one a reasonable chance, often not even an awareness of their approach. Destruction can strike out of the blue skies and destroy thousands like the bomb at Hiroshima; it may come in the form of gases or other means of chemical warfare—invisible, crippling, killing. It is no longer the man who fights for his rights, his convictions, or the safety or honor of his family, it is the nation including its women and children who are in the war, affected directly or indirectly without a chance of survival. This is how science and technology have contributed to an ever increasing fear of destruction and therefore fear of death.

Is it surprising, then, that man has to defend himself more? If his ability to defend himself physically is getting smaller and smaller, his psychological defenses have to increase manifoldly. He cannot maintain denial forever. He cannot continuously and successfully pretend that he is safe. If we cannot deny death we may attempt to master it. We may join the race on the highways, we may read the death toll over national holidays and shudder, but also rejoice—"It was the other guy, not me, I made it."

Groups of people, from street gangs to nations, may use their group identity to express their fear of being destroyed by attacking and destroying others. Is war perhaps nothing else but a need to face death, to conquer and master it, to come out of it alive—a peculiar form of denial of our own mortality? One of our patients dying of leukemia said in utter disbelief: "It is impossible for me to die now. It cannot be God's will, since he let me survive when I was hit by bullets just a few feet away during World War II."

Another woman expressed her shock and sense of incredulity when she described the "unfair death" of a young man who was on leave from Vietnam and met his death in a car accident, as if

his survival on the battlefield was supposed to have guaranteed immunity from death back home.

A chance for peace may thus be found in studying the attitudes toward death in the leaders of the nations, in those who make the final decisions of war and peace between nations. If all of us would make an all-out effort to contemplate our own death, to deal with our anxieties surrounding the concept of our death, and to help others familiarize themselves with these thoughts, perhaps there could be less destructiveness around us.

News agencies may be able to contribute their share in helping people face the reality of death by avoiding such depersonalized terms as the "solution of the Jewish question" to tell of the murder of millions of men, women, and children; or to use a more recent issue, the recovery of a hill in Vietnam through elimination of a machine gun nest and heavy loss of VC could be described in terms of human tragedies and loss of human beings on both sides. There are so many examples in all newspapers and other news media that it is unnecessary to add more here.

In summary, then, I think that with rapid technical advancement and new scientific achievements men have been able to develop not only new skills but also new weapons of mass destruction which increase the fear of a violent, catastrophic death. Man has to defend himself psychologically in many ways against this increased fear of death and increased inability to foresee and protect himself against it. Psychologically he can deny the reality of his own death for a while. Since in our unconscious we cannot perceive our own death and do believe in our own immortality, but can conceive our neighbor's death, news of numbers of people killed in battle, in wars, on the highways only support our unconscious belief in our own immortality and allow us—in the privacy and secrecy of our unconscious mind—to rejoice that it is "the next guy, not me."

If denial is no longer possible, we can attempt to master death by challenging it. If we can drive the highways at rapid speed, if we can come back home from Vietnam, we must indeed feel immune to death. We have killed ten times the number of enemies compared to our own losses—we hear on the news almost daily. Is this our wishful thinking, our projection of our infantile wish for omnipotence and immortality? If a whole nation, a whole society suffers from such a fear and denial of death, it has to use defenses which can only be destructive. Wars, riots, and increasing numbers of murders and other crimes may be

indicators of our decreasing ability to face death with acceptance and dignity. Perhaps we have to come back to the individual human being and start from scratch, to attempt to conceive our own death and learn to face this tragic but inevitable happening with less irrationality and fear.

What role has religion played in these changing times? In the old days more people seemed to believe in God unquestionably; they believed in a hereafter, which was to relieve people of their suffering and their pain. There was a reward in heaven, and if we had suffered much here on earth we would be rewarded after death depending on the courage and grace, patience and dignity with which we had carried our burden. Suffering was more common, as childbirth was a more natural, long and painful event—but the mother was awake when the child was born. There was a purpose and future reward in the suffering. Now we sedate mothers, try to avoid pain and agony; we may even induce labor to have a birth occur on a relative's birthday or to avoid interference with another important event. Many mothers only wake up hours after the babies are born, too drugged and sleepy to rejoice the birth of their children. There is not much sense in suffering, since drugs can be given for pain, itching, and other discomforts. The belief has long died that suffering here on earth will be rewarded in heaven. Suffering has lost its meaning.

But with this change, also, fewer people really believe in life after death, in itself perhaps a denial of our mortality. Well, if we cannot anticipate life after death, then we have to consider death. If we are no longer rewarded in heaven for our suffering, then suffering becomes purposeless in itself. If we take part in church activities in order to socialize or to go to a dance, then we are deprived of the church's former purpose, namely, to give hope, a purpose in tragedies here on earth, and an attempt to understand and bring meaning to otherwise unacceptable painful occurrences in our life.

Paradoxical as it may sound, while society has contributed to our denial of death, religion has lost many of its believers in a life after death, i.e., immortality, and thus has decreased the denial of death in that respect. In terms of the patient, this has been a poor exchange. While the religious denial, i.e., the belief in the meaning of suffering here on earth and reward in heaven after death, has offered hope and purpose, the denial of society has given neither hope nor purpose but has only increased our anxiety and contributed to our destructiveness and

aggressiveness—to kill in order to avoid the reality and facing of our own death.

A look into the future shows us a society in which more and more people are “kept alive” both with machines replacing vital organs and computers checking from time to time to see if some additional physiologic functionings have to be replaced by electronic equipment. Centers may be established in increasing numbers where all the technical data is collected and where a light may flash up when a patient expires in order to stop the equipment automatically.

Other centers may enjoy more and more popularity where the deceased are quickly deep-frozen to be placed in a special building of low temperature, awaiting the day when science and technology have advanced enough to defrost them, to return them to life and back into society, which may be so frighteningly over-populated that special committees may be needed to decide how many can be defrosted, just as there are committees now to decide who shall be the recipient of an available organ and who shall die.

It may sound all very horrible and incredible. The sad truth, however, is that all this is happening already. There is no law in this country that prevents business-minded people from making money out of the fear of death, that denies opportunists the right to advertise and sell at high cost a promise for possible life after years of deep-freeze. These organizations exist already, and while we may laugh at people who ask whether a widow of a deep-frozen person is entitled to accept social security or to remarry, the questions are all too serious to be ignored. They actually show the fantastic degrees of denial that some people require in order to avoid facing death as a reality, and it seems time that people of all professions and religious backgrounds put their heads together before our society becomes so petrified that it has to destroy itself.

Now that we have taken a look into the past with man’s ability to face death with equanimity and a somewhat frightening glimpse into the future, let us come back to the present and ask ourselves very seriously what we as individuals can do about all this. It is clear that we cannot avoid the trend toward increasing numbers altogether. We live in a society of the mass man rather than the individual man. The classes in the medical schools will get bigger, whether we like it or not. The number of cars on the highways will increase. The number of people being kept alive

will increase, if we consider only the advancement in cardiology and cardiac surgery.

Also, we cannot go back in time. We cannot afford every child the learning experience of a simple life on a farm with its closeness to nature, the experience of birth and death in the natural surrounding of the child. Men of the churches may not even be successful in bringing many more people back to the belief in a life after death which would make dying more rewarding though through a form of denial of mortality in a sense.

We cannot deny the existence of weapons of mass destruction nor can we go back in any way or sense in time. Science and technology will enable us to replace more vital organs, and the responsibility of questions concerning life and death, donors and recipients will increase manifoldly. Legal, moral, ethical, and psychological problems will be posed to the present and future generation which will decide questions of life and death in ever increasing numbers until these decisions, too, will probably be made by computers.

Though every man will attempt in his own way to postpone such questions and issues until he is forced to face them, he will only be able to change things if he can start to conceive of his own death. This cannot be done on a mass level. This cannot be done by computers. This has to be done by every human being alone. Each one of us has the need to avoid this issue, yet each one of us has to face it sooner or later. If all of us could make a start by contemplating the possibility of our own personal death, we may effect many things, most important of all the welfare of our patients, our families, and finally perhaps our nation.

If we could teach our students the value of science and technology simultaneously with the art and science of inter-human relationships, of human and total patient-care, it would be real progress. If science and technology are not to be misused to increase destructiveness, prolonging life rather than making it more human, if they could go hand in hand with freeing more time rather than less for individual person-to-person contacts, then we could really speak of a great society.

Finally, we may achieve peace—our own inner peace as well as peace between nations—by facing and accepting the reality of our own death.

An example of combined medical, scientific achievement and humanity is given in the following case of Mr. P.:

Mr. P. was a fifty-one-year-old patient who was hospitalized with rapidly progressing amyotrophic lateral sclerosis with bulbar involvement. He was unable to breathe without a respirator, had difficulties coughing up any sputum, and developed pneumonia and an infection at the site of his tracheostomy. Because of the latter he was also unable to speak; thus he would lie in bed, listening to the frightening sound of the respirator, unable to communicate to anybody his needs, thoughts, and feelings. We might have never called on this patient had it not been for one of the physicians who had the courage to ask for help for himself. One Friday evening he visited us and asked simply for some support, not for the patient primarily but for himself. While we sat and listened to him, we heard an account of feelings that are not often spoken about. The doctor was assigned to this patient on admission and was obviously impressed by this man's suffering. His patient was relatively young and had a neurological disorder which required immense medical attention and nursing care in order to extend his life for a short while only. The patient's wife had multiple sclerosis and had been paralyzed in all limbs for the past three years. The patient hoped to die during this admission as it was inconceivable for him to have two paralyzed people at home, each watching the other without the ability to care for the other.

This double tragedy resulted in the physician's anxiety and in his overly vigorous efforts to save this man's life "no matter in what condition." The doctor was quite aware that this was contrary to the patient's wishes. His efforts continued successfully even after a coronary occlusion which complicated the picture. He fought it as successfully as he fought the pneumonia and infections. When the patient began to recover from all the complications, the question arose—"What now?" He could live only on the respirator with twenty-four-hour nursing care, unable to talk or move a finger, alive intellectually and fully aware of his predicament but otherwise unable to function. The doctor picked up implicit criticism of his attempts to save this man. He also elicited the patient's anger and frustration at him. What was he supposed to do? Besides, it was too late to change matters. He had wished to do his best as a physician to prolong life and now that he had succeeded, he elicited

nothing but criticism (real or unreal) and anger from the patient.

We decided to attempt to solve the conflict in the patient's presence since he was an important part of it. The patient looked interested when we told him of the reason for our visit. He was obviously satisfied that we had included him, thus regarding and treating him as a person in spite of his inability to communicate. In introducing the problem I asked him to nod his head or to give us another signal if he did not want to discuss the matter. His eyes spoke more than words. He obviously struggled to say more and we were looking for means of allowing him to take his part. The physician, relieved by sharing his burden, became quite inventive and deflated the respirator tube for a few minutes at a time which allowed the patient to speak a few words while exhaling. A flood of feelings were expressed in these interviews. He emphasized that he was not afraid to die, but was afraid to live. He also empathized with the physician but demanded of him "to help me live now that you so vigorously tried to pull me through." The patient smiled and the physician smiled.

There was a great relief of tension in the air when the two were able to talk to each other. I rephrased the doctor's conflicts with which the patient sympathized. I asked him how we could be of the most help to him now. He described his increasing panic when he was unable to communicate by speaking, writing, or other means. He was grateful for those few minutes of joint effort and communication which made the next weeks much less painful. At a later session I observed with pleasure how the patient even considered a possible discharge and planned on a transfer to the West Coast "if I can get the respirator and the nursing care there."

This example perhaps best shows the predicament that many young physicians find themselves in. They learn to prolong life but get little training or discussion in the definition of "life." This patient regarded himself appropriately as "dead up to my head," the tragedy being that he was intellectually fully aware of his position and unable to move a single finger. When the tube pressured and hurt him, he was unable to tell it to the nurse, who was with him around the clock but was unable to learn to communicate. We often take for granted that "there is nothing

one can do” and focus our interests on the equipment rather than on the facial expressions of the patient, which can tell us more important things than the most efficient machine. When the patient had an itch, he was unable to move or rub or blow and became preoccupied with this inability until it took on panic proportions which drove him “near insanity.” The introduction of this regular five-minute session made the patient calm and better able to tolerate his discomforts.

This relieved the physician of his conflicts and insured him of a better relationship without guilt or pity. Once he saw how much ease and comfort such direct explicit dialogues can provide, he continued them on his own, having used us merely as a kind of catalyst to get the communication going.

I feel strongly that this should be the case. I do not feel it beneficial that a psychiatrist be called each time a patient-doctor relationship is in danger or a physician is unable or unwilling to discuss important issues with his patient. I found it courageous and a sign of great maturity on the part of this young doctor to acknowledge his limits and his conflicts and seek help rather than to avoid the issue and the patient. Our goals should not be to have specialists for dying patients but to train our hospital personnel to feel comfortable in facing such difficulties and to seek solutions. I am confident that this young physician will have much less turmoil and conflict when he is faced with such tragedies the next time. He will attempt to be a physician and prolong life but also consider the patient’s needs and discuss them frankly with him. This patient, who was still a person, was only unable to bear to live because he was unable to make use of the faculties that he had left. With combined efforts many of these faculties can be used if we are not frightened away by the mere sight of such a helpless, suffering individual. Perhaps what I am saying is that we can help them die by trying to help them live, rather than vegetate in an inhuman manner.

*The Beginning of an Interdisciplinary Seminar on
Death and Dying*

In the fall of 1965 four theology students of the Chicago Theological Seminary approached me for assistance in a research project they had chosen. Their class was to write a paper on “crisis in human life,” and the four students considered death as the biggest crisis people had to face. Then the natural question arose:

How do you do research on dying, when the data is so impossible to get? When you cannot verify your data and cannot set up experiments? We met for a while and decided that the best possible way we could study death and dying was by asking terminally ill patients to be our teachers. We would observe critically ill patients, study their responses and needs, evaluate the reactions of the people around them, and get as close to the dying as they would allow us.

We decided to interview a dying patient the following week. We agreed on time and place, and the whole project seemed rather simple and uncomplicated. Since the students had no clinical experience and no past encounter with terminally ill patients in a hospital, we expected some emotional reaction on their part. I was to do the interview while they stood around the bed watching and observing. We would then retire to my office and discuss our own reactions and the patient's response. We believed that by doing many interviews like this we would get a feeling for the terminally ill and their needs which in turn we were ready to gratify if possible.

We had no other preconceived ideas nor did we read any papers or publications on this topic so that we might have an open mind and record only what we ourselves were able to notice, both in the patient and in ourselves. We also purposely did not study the patient's chart since this too might dilute or alter our own observations. We did not want to have any preconceived notion as to how the patients might react. We were quite prepared, however, to study all available data after we had recorded our own impressions. This, we thought, would sensitize us to the needs of the critically ill, would enhance our perceptiveness and, we hoped, desensitize the rather frightened students through an increasing number of confrontations with terminally ill patients of different ages and backgrounds.

We were well satisfied with our plans and it was not until a few days later that our difficulties started.

I set out to ask physicians of different services and wards for permission to interview a terminally ill patient of theirs. The reactions were varied, from stunned looks of disbelief to rather abrupt changes of topic of conversation; the end result being that I did not get one single chance even to get near such a patient. Some doctors "protected" their patients by saying that they were too sick, too tired or weak, or not the talking kind; others bluntly refused to take part in such a project. I have to add in their

defense that they were justified to some degree, as I had just started my work in this hospital and no one had had a chance to know me or my style and type of work. They had no assurance, except from me, that the patients were not to be traumatized, that those who had not been told of the seriousness of their illness would not be told. Also, these physicians were not aware of my past experience with the dying in other hospitals.

I have added this in order to present their reactions as fairly as I can. These doctors were both very defensive when it came to talking about death and dying and also protective of their patients in order to avoid a traumatic experience with a yet unknown faculty member who had just joined their ranks. It suddenly seemed that there were no dying patients in this huge hospital. My phone calls and personal visits to the wards were all in vain. Some physicians said politely that they would think about it, others said they did not wish to expose their patients to such questioning as it might tire them too much. A nurse angrily asked in utter disbelief if I enjoyed telling a twenty-year-old man that he had only a couple of weeks to live! She walked away before I could tell her more about our plans.

When we finally had a patient, he welcomed me with open arms. He invited me to sit down and it was obvious that he was eager to speak. I told him that I did not wish to hear him now but would return the next day with my students. I was not sensitive enough to appreciate his communications. It was so hard to get one patient, I had to share him with my students. Little did I realize then that when such a patient says "Please sit down *now*," tomorrow may be too late. When we revisited him the next day, he was lying back in his pillow, too weak to speak. He made a meager attempt to lift his arm and whispered "Thank you for trying"—he died less than an hour later and kept to himself what he wanted to share with us and what we so desperately wanted to learn. It was our first and most painful lesson, but also the beginning of a seminar which was to start as an experiment and ended up to be quite an experience for many.

The students met with me in my office after this encounter. We felt the need to talk about our own experience and wanted to share our reactions in order to understand them. This procedure is continued until the present day. Technically little has changed in that respect. We still see a terminally ill patient once a week. We ask him for permission to tape-record the dialogue and leave up to him entirely how long he feels like talking. We have moved

from the patient's room to a little interviewing room from which we can be seen and heard but we do not see the audience. From a group of four theology students the class has grown to up to fifty, which necessitated the move to a screen window set-up.

When we hear of a patient who may be available for the seminar, we approach him either alone or with one of the students and the referring physician or hospital chaplain, or both. After a brief introduction we state the purpose and timing of our visit, clearly and concretely. I tell each patient that we have an interdisciplinary group of hospital personnel eager to learn from the patient. We emphasize that we need to know more about the very sick and dying patient. We then pause and await the patient's verbal or nonverbal reactions. We do this only after the patient has invited us to talk. A typical dialogue follows:

DOCTOR: Hello Mr. X. I am Dr. R. and this is Chaplain N. Do you feel like talking for a little while?

PATIENT: Please, by all means, sit down.

DOCTOR: We are here with a peculiar request. Chaplain N. and I are working with a group of people from the hospital who are trying to learn more about very sick and dying patients. I wonder if you feel up to answering some of our questions?

PATIENT: Why don't you ask and I'll see if I can answer them.

DOCTOR: How sick are you?

PATIENT: I am full of metastasis....

(Another patient may say, "Do you really want to talk to an old and dying woman? You are young and healthy!")

Others are not so receptive at first. They start complaining about their pain, their discomfort, their anger, until they are in the midst of sharing their agony. We then remind them that this is exactly what we wanted the others to hear and would they consider repeating the same a little time later.

When the patient agrees, the doctor has granted permission, and arrangements have been made, the patient is brought personally by us to the interviewing room. Very few of them walk, most are in wheelchairs, a few have to be carried on a stretcher. Where infusions and transfusions are necessary, they are brought along. Relatives have not been included, though they have occasionally been interviewed following the dialogue with the patient.

Our interviews keep in mind that no one present has much if any background information on the patient. We usually rephrase the purpose of the interview on our way to the interviewing room during which time we emphasize the patient's right to stop the session at any moment for any reason of his own. We again describe the mirror on the wall which makes it possible for the audience to see and hear us and this allows the patient a moment of privacy with us which is often used to alleviate last-minute concerns and fears.

Once in the interviewing room the conversation flows easily and quickly, starting with general information and going on to very personal concerns as shown in actual recorded interviews, a few of which are presented in this book.

Following each session the patient is first brought back to his room after which the seminar continues. No patient is kept waiting in the hallways. When the interviewer has returned to the classroom he joins the audience and together we discuss the event. Our own spontaneous reactions are brought to light, no matter how appropriate or irrational. We discuss our different responses, both emotional and intellectual. We discuss the patient's response to different interviewers and different questions and approaches and finally attempt a psychodynamic understanding of his communications. We study his strengths and weaknesses as well as ours in the management of this given person and conclude by recommending certain approaches that we hope will make the patient's final days or weeks more comfortable.

None of our patients has died during the interview. Survival ranged from twelve hours to several months. Many of our more recent patients are still alive and many of the very critically ill patients have had a remission and have gone home once more. Several of them have had no relapse and are doing well. I emphasize this since we are talking about dying with patients who are not actually dying in the classical sense of the word. We are talking with many if not most of them about this event because it is something that they have faced because of the occurrence of a usually fatal illness—our intervention may take place at any time between the making of the diagnosis until just before death.

The discussion serves many purposes, as we have found out by experience. It has been most helpful in making the students aware of the necessity of considering death as a real possibility,

not only for others but also for themselves. It has proven to be a meaningful way of desensitization, which comes slowly and painfully. Many a student appearing for the first time has left before the interview was over. Some were finally able to sit through a whole session but were unable to express their opinions in the discussion. Some of them have displaced all their anger and rage onto other participants or the interviewer, at times onto the patients. The last has occasionally happened when a patient apparently faced death with calmness and equanimity while the student was highly upset by the encounter. The discussion then revealed that the student thought the patient was unrealistic or even faking, because it was inconceivable to him that anyone could face such a crisis with so much dignity.

Other participants began to identify with the patients, especially if they were of the same age and had to deal with these conflicts in the discussion—and long afterwards. As those in the group began to know each other and realized that nothing was taboo, the discussions became a sort of group therapy for the participants, with many frank confrontations, mutual support, and at times painful discoveries and insights. Little did the patients realize the impact and long-lasting effects many of the communications had on a great variety and number of students.

Two years after the creation of this seminar, it became an accredited course for the medical school and the theological seminary. It is also attended by many visiting physicians, by nurses and nurses' aids, orderlies, social workers, priests and rabbis, by inhalation therapists and occupational therapists, but only rarely by faculty members of our own hospital. The medical and theology students who take it as a formal credit course are also attending a theoretical session, which deals with theory, philosophical, moral, ethical, and religious questions, and which is alternately held by the author and the hospital chaplain.

All interviews are tape-recorded and remain available to students and teachers. At the end of each quarter each student writes a paper on a subject of his own choice. These papers will be presented in a future publication; they range from very personal workings-through of concepts and fears of death to highly philosophical, religious, or sociological papers dealing with death and dying.

In order to ensure confidentiality, a checklist is made of all those attending, and names and identifying data are altered on all transcribed recordings.

From an informal get-together of four students, a seminar has grown within two years which is attended by as many as fifty people consisting of members of all the helping professions. Originally it took an average of ten hours a week to get permission from a doctor to ask a patient to be interviewed; now we are rarely forced to search for a patient. We are getting referrals from physicians, nurses, social workers, and most encouragingly, perhaps, from patients who have attended the seminar and have shared their experience with other terminally ill patients who then ask to attend, at times to do us a service, at other times in order to be heard.

The Dying As Teachers

To tell or not to tell, that is the question.

In talking to physicians, hospital chaplains, and nursing staff, we are often impressed about their concern for a patient's tolerance of "the truth." "Which truth?" is usually our question. The confronting of patients after the diagnosis of a malignancy is made is always difficult. Some physicians favor telling the relatives but keeping the facts from the patient in order to avoid an emotional outburst. Some doctors are sensitive to their patient's needs and can quite successfully present the patient with the awareness of a serious illness without taking all hope away from him.

I personally feel that this question should never come up as a real conflict. The question should not be "Should we tell...?" but rather "How do I share this with my patient?" I will try to explain this attitude in the following pages. I will therefore have to categorize crudely the many experiences that patients have when they are faced with the sudden awareness of their own finality. As we have outlined previously, man is not freely willing to look at his own end of life on earth and will only occasionally and half-heartedly take a glimpse at the possibility of his own death. One such occasion, obviously, is the awareness of a life-threatening illness. The mere fact that a patient is told that he has cancer brings his possible death to his conscious awareness.

It is often said that people equate a malignancy with terminal illness and regard the two as synonymous. This is basically true and can be a blessing or a curse, depending on the manner in which the patient and family are managed in this crucial situation. Cancer is still for most people a terminal illness, in spite of

increasing numbers of real cures as well as meaningful remissions. I believe that we should make it a habit to think about death and dying occasionally, I hope before we encounter it in our own life. If we have not done so, the diagnosis of cancer in our family will brutally remind us of our own finality. It may be a blessing, therefore, to use the time of illness to think about death and dying in terms of ourselves, regardless of whether the patient will have to meet death or get an extension of life.

If a doctor can speak freely with his patients about the diagnosis of malignancy without equating it necessarily with impending death, he will do the patient a great service. He should at the same time leave the door open for hope, namely, new drugs, treatments, chances of new techniques and new research. The main thing is that he communicates to the patient that all is not lost; that he is not giving him up because of a certain diagnosis; that it is a battle they are going to fight together—patient, family, and doctor—no matter the end result. Such a patient will not fear isolation, deceit, rejection, but will continue to have confidence in the honesty of his physician and know that if there is anything that can be done, they will do it together. Such an approach is equally reassuring to the family who often feel terribly impotent in such moments. They greatly depend on verbal or nonverbal reassurance from the doctor. They are encouraged to know that everything possible will be done, if not to prolong life at least to diminish suffering.

If a patient comes in with a lump in the breast, a considerate doctor will prepare her with the possibility of a malignancy and tell her that a biopsy, for example, will reveal the true nature of the tumor. He will also tell her ahead of time that a more extensive surgery will be required if a malignancy is found. Such a patient has more time to prepare herself for the possibility of a cancer and will be better prepared to accept more extensive surgery should it be necessary. When the patient awakens from the surgical procedure the doctor can say, "I am sorry, we had to do the more extensive surgery." If the patient responds, "Thank God, it was benign," he can simply say, "I wish that were true," and then silently sit with her for a while and not run off. Such a patient may pretend not to know for several days. It would be cruel for a physician to force her to accept the fact when she clearly communicates that she is not yet ready to hear it. The fact that he has told her once will be sufficient to maintain confidence in the doctor. Such a patient will seek him out later when she is

able and strong enough to face the possible fatal outcome of her illness.

Another patient's response may be, "Oh, doctor, how terrible, how long do I have to live?" The physician may then tell her how much has been achieved in recent years in terms of extending the life span of such patients, and about the possibility of additional surgery which has shown good results; he may tell her frankly that nobody knows how long she can live. I think it is the worst possible management of any patient, no matter how strong, to give him a concrete number of months or years. Since such information is wrong in any case, and exceptions in both directions are the rule, I see no reason why we even consider such information. There may be a need in some rare instances where a head of a household should be informed of the shortness of his expected life in order to bring his affairs in order. I think even in such cases a tactful, understanding physician can communicate to his patient that he may be better off putting his affairs in order while he has the leisure and strength to do so, rather than to wait too long. Such a patient will most likely get the implicit message while still able to maintain the hope which each and every patient has to keep, including the ones who say that they are ready to die. Our interviews have shown that all patients have kept a door open to the possibility of continued existence, and not one of them has at all times maintained that there is no wish to live at all.

When we asked our patients how they had been told, we learned that all the patients knew about their terminal illness anyway, whether they were explicitly told or not, but depended greatly on the physician to present the news in an acceptable manner.

What, then, is an acceptable manner? How does a physician know which patient wants to hear it briefly, which one with a long scientific explanation, and which one wants to avoid the issue all together? How do we know when we do not have the advantage of knowing the patient well enough before being confronted with such decisions?

The answer depends on two things. The most important one is our own attitude and ability to face terminal illness and death. If this is a big problem in our own life, and death is viewed as a frightening, horrible, taboo topic, we will never be able to face it calmly and helpfully with a patient. And I say "death" on purpose, even if we only have to answer the question of malignancy or no malignancy. The former is always associated with impending death, a destructive nature of death, and it is the former that

evokes all the emotions. If we cannot face death with equanimity, how can we be of assistance to our patients? We, then, hope that our patients will not ask us this horrible question. We make rounds and talk about many trivialities or the wonderful weather outside and the sensitive patient will play the game and talk about next spring, even if he is quite aware that there will be no next spring for him. These doctors then, when asked, will tell us that their patients do not want to know the truth, that they never ask for it, and that they believe all is well. The doctors are, in fact, greatly relieved that they are not confronted and are often quite unaware –that they provoked this response in their patients.

Doctors who are still uneasy about such discussions but not so defensive may call a chaplain or priest and ask him to talk to the patient. They may feel more at ease having passed on the difficult responsibility to someone else, which may be better than avoiding it altogether. They may, on the other hand, be so anxious about it that they leave explicit orders to the staff and chaplain not to tell the patient. The degree of explicitness in such orders will reveal more about the doctors' anxiety than they wish to recognize.

There are others who have less difficulty with this issue and who find a much smaller number of patients unwilling to talk about their serious illness. I am convinced, from the many patients with whom I have spoken about this matter, that those doctors who need denial themselves will find it in their patients and that those who can talk about the terminal illness will find their patients better able to face and acknowledge it. The need of denial is in direct proportion with the doctor's need for denial. But this is only half of the problem.

We have found that different patients react differently to such news depending on their personality makeup and the style and manner they used in their past life. People who use denial as a main defense will use denial much more extensively than others. Patients who faced past stressful situations with open confrontation will do similarly in the present situation. It is, therefore, very helpful to get acquainted with a new patient, in order to elicit his strengths and weaknesses. I will give an example of this:

Mrs. A., a thirty-year-old white woman. asked us to see her during her hospitalization. She presented herself as a short, obese, pseudo-gay woman who smilingly told us of her

“benign lymphoma” for which she had received a variety of treatments including cobalt and nitrogen mustard, known by most people in the hospital to be given for malignancies. She was very familiar with her illness and readily acknowledged having read the literature about it. She suddenly became quite weepy and told a rather pathetic story of how her doctor at home told her of her “benign lymphoma” after receiving the biopsy results. “A benign lymphoma?” I repeated, expressing some doubt in my voice and then sitting quietly for an answer. “Please, doctor, tell me whether it’s malignant or benign?” she asked but without waiting for my answer, she began a story of a fruitless attempt to get pregnant. For nine years she had hoped for a baby, she went through all possible tests, finally through agencies in the hope of adopting a child. She was turned down for many reasons, first because she had been married only two and a half years, later because of emotional instability perhaps. She had not been able to accept the fact that she could not even have an adopted child. Now she was in the hospital and was forced to sign a paper for radiation treatment with the explicit statement that this would result in sterility, thus rendering her finally and irrevocably unable to bear a child. It was unacceptable to her in spite of the fact that she had signed the paper and had undergone the preliminary work-up for the radiation. Her abdomen was marked and she was to have her first treatment the following morning.

This communication revealed to me that she was not able to accept the fact yet. She asked the question of the malignancy but did not wait for an answer. She also told me of her inability to accept the fact of her childlessness in spite of her acceptance of the radiation treatment. She went on at great length to tell about all the details of her unfulfilled wish and kept on looking at me with big question marks in her eyes. I told her that she might be talking about her inability to face her illness rather than her inability to face being barren. I told her that I could understand this. I also said that both situations were difficult but not hopeless and left her with the promise to return the next day after the treatment.

It was on the way to the first radiation treatment that she confirmed her knowledge of her malignancy, but she hoped that this treatment might cure it. During the following

informal, almost social visits, she fluctuated between talking about babies and her malignancy. She became increasingly tearful and dropped her pseudo-gay appearance during these sessions. She asked for a "magic button" which would enable her to get rid of all her fears and free her from the heavy burden in her chest. She was deeply concerned about the expected new roommate, "worrying to death" as she called it that she would get a terminally sick woman. Since the nursing staff on her ward was very understanding, we related her fears to them, and she became the companion of a cheerful young woman who was a great relief to her. The nursing staff also encouraged her to cry when she felt like it, rather than expecting her to smile all the time, which the patient appreciated. She had a great capacity to determine with whom she could talk about her malignancy and chose the less willing ones for her conversations about babies. The staff was quite surprised to hear of her awareness and ability to discuss her future realistically.

It was after a few very fruitful visits that the patient suddenly asked me if I had children and when I acknowledged this, she asked to terminate the visit because she was tired. The following visits were filled with angry, nasty remarks at the nursing staff, psychiatrists, and others until she was able to admit her feelings of envy for the healthy and the young, but especially towards me since I seemed to have everything. When she realized that she was not rejected in spite of becoming at times a rather difficult patient, she became increasingly aware of the origin of her anger and expressed it quite directly as anger at God for allowing her to die so young and so unfulfilled. The hospital chaplain fortunately was not a punitive but a very understanding man and talked with her about this anger in much the same terms as I did until her anger subsided to make room for more depression and, it is hoped, final acceptance of her fate.

Until the present time, this patient still maintains this dichotomy in regard to her chief problem. To one group of people she only relates as a conflicted woman in terms of her childlessness; to the chaplain and me, she talks about the meaning of her short life and the hopes she still maintains (rightfully so) for prolonging it. Her greatest fear at the time of this writing is the possibility of her husband

marrying another woman who might bear children, but then she laughingly admits, "He is not the shah of Persia, though a really great man." She still has not completely coped with her envy for the living. The fact that she does not need to maintain denial or displace it onto another tragic but more acceptable problem allows her to deal with her illness more successfully.

Another example of a problem of "to tell or not to tell" is Mr. D., of whom nobody was sure whether he knew the nature of his illness. The staff was convinced that the patient did not know the great seriousness of his condition, since he never allowed anybody to get close to him. He never asked a question about it, and seemed in general rather feared by the staff. The nurses were ready to bet that he would never accept an invitation to discuss the matter with me. Anticipating difficulties, I approached him hesitantly and asked him simply, "How sick are you?" "I am full of cancer..." was his answer. The problem with him was that nobody ever asked a simple straightforward question. They mistook his grim look as a closed door; in fact, their own anxiety prevented them from finding out what he wanted to share so badly with another human being.

If malignancy is presented as a hopeless disease which results in a sense of "what's the use, there is nothing we can do anyway," it will be the beginning of a difficult time for the patient and for those around him. The patient will feel the increasing isolation, the loss of interest on part of his doctor, the isolation and increasing hopelessness. He may rapidly deteriorate or fall into a deep depression from which he may not emerge unless someone is able to give him a sense of hope.

The family of such patients may share their feelings of sorrow and uselessness, hopelessness and despair, and add little to the patient's well-being. They may spend the short remaining time in a morbid depression instead of an enriching experience which is often encountered when the physician responds as outlined earlier.

I have to emphasize, though, that the patient's reaction does not depend solely on how the doctor tells him. The way in which the bad news is communicated is, however, an important factor which is often underestimated and which should be given more emphasis in the teaching of medical students and supervision of young physicians.

In summary, then, I believe the question should not be stated, "Do I tell my patient?" but should be rephrased as, "How do I share this knowledge with my patient?" The physician should first examine his own attitude toward malignancy and death so that he is able to talk about such grave matters without undue anxiety. He should listen for cues from the patient which enable him to elicit the patient's willingness to face the reality. The more people in the patient's environment who know the diagnosis of a malignancy, the sooner the patient himself will realize the true state of affairs anyway, since few people are actors enough to maintain a believable mask of cheerfulness over a long period of time. Most if not all of the patients know anyway. They sense it by the changed attention, by the new and different approach that people take to them, by the lowering of voices or avoidance of rounds, by a tearful face of a relative or an ominous, smiling member of the family who cannot hide their true feelings. They will pretend not to know when the doctor or relative is unable to talk about their true condition, and they will welcome someone who is willing to talk about it but allows them to keep their defenses as long as they have the need for them.

Whether the patient is told explicitly or not, he will nevertheless come to this awareness and may lose confidence in a doctor who either told him a lie or who did not help him face the seriousness of his illness while there might have been time to get his affairs in order.

It is an art to share this painful news with any patient. The simpler it is done, the easier it is usually for a patient who recollects it at a later date, if he can't "hear it" at the moment. Our patients appreciated it when they were told in the privacy of a little room rather than being told in the hallway of a crowded clinic.

What all of our patients stressed was the sense of empathy which counted more than the immediate tragedy of the news. It was the reassurance that everything possible will be done, that they will not be "dropped," that there were treatments available, that there was a glimpse of hope—even in the most advanced cases. If the news can be conveyed in such a manner, the patient will continue to have confidence in the doctor, and he will have time to work through the different reactions which will enable him to cope with this new and stressful life situation.

In the following pages is an attempt to summarize what we have learned from our dying patients in terms of coping mechanisms at the time of a terminal illness.

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