Death and the Inexorably Dying: A Seminar

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Introduction:

DR. KINGMA: The topic we have set out to explore today is the knotty problem of how we feel about dying, or more specifically, how we feel about it for our patients. Some two or three years ago, it could have been said that death had replaced sex as the most socially taboo topic. Curiously, it has become a subject of rather remarkable exposure in the last year or so. No less than four major TV series have featured programs on the dying patient and his doctor. One of the most prominent national figures in this arena, Dr. Elisabeth Kubler-Ross, is an exceedingly popular seminar speaker and lecturer on this subject. And yet, in medical schools and medical centers around the country, the great uncomfortable silence persists. There is little or no formal attention paid to this subject. This is understandable since very few people are prepared to face the fact of their own death, much less help their patients do so.

And so this next hour will focus on the humanity of the dying patient; we will seek to understand him and help him to cope with his dying. We will also examine ourselves, to better understand our discomfiture in the face of the dying, so that we may deal with them rationally and sympathetically.

This topic of the dying patient has largely been avoided in the forum of large medical centers, with few exceptions. One and a half years ago, a three-day conference was held at the New York Academy of Sciences, and the proceedings of this meeting were published in the Annals of the New York Academy. The second exception is a two-day conference held this week.
at the Rochester General Hospital with a broad-based panel gleaned from the entire country. But, in the main, open discussion of this subject is largely avoided. Dr. von Brauchitsch has an interesting observation on this point.

**DR. VON BRAUCHITSCH:** Not really my observation. I happened to see a paper recently in which the investigators commented on the increasing numbers of papers published about the dying patient. They investigated the degree to which these papers influence the medical community; their conclusion was that, though more papers are written, few of them are being read by physicians, or if they are being read, it is not reflected by changes in the attitudes and everyday practice of the physician.

**The Initial Encounter with the Fatally Ill Patient**

**DR. KINGMA:** What is the first level of contact that we make with the patient sick with a fatal illness? I suppose it's your first conversation after the diagnosis is confirmed. How then do you approach this patient? And, who decides what the patient is told? The relatives would like to decide that, and they will tell you that Mama can't stand to hear that she's got cancer. They take it out of the patient's hands. Maybe you want to decide what you tell the patient. Maybe you've had three days to assess this person, and you think it's your prerogative to decide whether or not this patient can tolerate the news. This is the recurring dilemma: What is the right of the patient to know the truth about his illness?

I think his first right is to be able to expect and depend on communication which is trustworthy from his doctor. The little lies that well-meaning relatives back you into will have to be repeated often, and end up shaking his trust in you when the ultimate course of the disease proves you a liar. This is one of the major problems of the fatally ill, being cut off from meaningful, trustworthy communication. The second right that your patient has in this circumstance is continuity of medical care. So often he goes from internist to surgeon to oncologist, and there is no one left to be personal physician to your patient, to tie the ends together for him and for his relatives. Even as specialists and consultants, we may not deprive the patient of the right to have a personal physician. Dr. von Brauchitsch, what about this relationship now between a patient and his physician?

**DR. VON BRAUCHITSCH:** Let me comment on the expression you used of "meaningful and trustworthy communication." It might not be as easy as that. Any patient who has a fatal illness, or any illness for that matter, usually reacts to this illness psychologically by regressing to an earlier level of psychological development. He relates in a more childlike way to his environment. Regression also allows him, to a very large degree, to totally ignore reality, the unpleasant reality, and replace it with fantasy.

Within these fantasy projections of the patient, the physician assumes an enormously important role. He becomes the crucial figure in the patient's life, not only in his real world, but also in a much more important, imagined role. Any casual comment or commu-
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Communication with the patient will be used by the patient to serve his emotional needs, often assuming an importance of which the physician himself really is not aware. This points out that the only way a meaningful and trustworthy communication between the patient and physician is possible, is for one physician to take the time and allow the patient to use him for his imaginary needs. He needs to see the patient daily in a one-to-one situation, and not just on rounds with three or four people milling around.

DR. KINGMA: Dr. O'Bryan, how do you discuss the problem of prognosis with a patient, particularly when metastases are present? And how do you discuss your program of chemotherapy with him?

DR. O'BRYAN: Cancer hits patients from all age groups and all levels of education and all cultural backgrounds, so that a monolithic approach to discussions with the patients simply won't work.

In general, we feel that a patient has to be told enough so that he can make an informed decision about how he is going to manage his life. Concepts should be kept simple; to be understood and avoid confusion, we do not use oversimplified folk-terms or unduly scientific names. We try always to be honest and avoid lies. Patients realize that we don't have all the answers. They must also realize that they can get the best available care should they choose it, and that they are not going to be shunned or avoided because they have a terminal disease.

In formulating a prognosis, we don't refer to a calendar of events as much as we do to the range of possibilities. We stress that cancer is a chronic illness and there is just no way to predict the exact time of death. To business executives and to responsible relatives, we are exact as we can be; to the usual patient, we keep the range broad and stress the positive aspects of the quality of survival.

In discussing metastases, we indicate that the size of the metastases may not be important, and that there are many people who have cancer cells in the bloodstream who lead a normal life span. For the most part, metastases mean that a tumor can no longer be cured, and that we must speak more in terms of palliation. We tell the patient that there are treatment programs available, and that they have helped many patients in the past. We do not usually discuss the cold statistics of regression rates with the patient, but we do inform a responsible relative of the expectations. We try as much as possible to stress the positive aspects of cancer control, to impart and encourage hope in the patient and his family. We are positive and enthusiastic in embarking on a treatment program, so that the patient gets no sense of hopelessness or abandonment.

DR. KINGMA: Father Wollard, how do you see yourself fitting into the pattern of continuing communication that our patients so badly need?

FATHER WOLLARD: The role of the chaplain in this instance is primarily one of helping the person to mobilize his own resources, both personal and family, medical and spiritual. The patient who is told his illness is terminal or fatal is always given more than he can handle immediately, and
he begins a slow process of assimilating what this means for him. Everyone who is dying goes through what we might call a kind of **grief for himself**, and each one moves through the phases of his grieving at his own pace. By stopping him when he talks about the process of dying or airily dismissing his questions about death, we prevent him from dealing with those aspects of death which trouble him. Patients are anxious at the prospect of pain or loneliness and often outraged at the loss of potential, the loss of future. Each of these concerns and many others need to be dealt with, slowly and patiently, time and again. Perhaps most important, the patient should be helped to realize he is not in fact dead but still alive, probably with a fair amount of living left to do, measured in months or sometimes even years. If he can make that transition from the focus on death back to a renewed perception of life, his last days or weeks or months can be among the most fruitful and enjoyable that he will spend.

One of the functions of religion is to help restore such a perspective, to help him **put death back into the perspective of life**, and to help him **face death with a renewed grasp of the worth of life**. We can’t do this for the patient but we can do it **with him**, and I think all can gain in that process.

**DR. KINGMA:** Professor Koenig, most physicians walk into that first interview with a patient who is known to be fatally ill, feeling very uncomfortable, and that discomfort frequently colors all the rest of our contacts with that patient. What’s going on between the patient and doctor here?

**PROFESSOR KOENIG:** Commonly what’s going on is not so much a problem in the relationship between the patient and the doctor, as it is a problem in the relationship of the doctor with himself. The very magnitude of death for the living obscures the issues that are important in the relationship between the doctor and his patient. Unfortunately, because it is more comfortable frequently for physicians to be in that position, they encourage the very regression that Dr. von Brauchitsch referred to. Somehow they communicate the feeling that because an individual is losing his life, he is at the same time losing his membership as a human in the human race. **The problem probably is one of honesty and the inability of the physician to honestly face his limitations as a technician.** This can be compounded when the physician is unable to face in a honest way his limitation as a person, beyond his simple professional role.

This raises the question of truth, truth in the sense that you needn’t tell a patient that he is dying. The process of dying is a process that patients experience in terms of losing their life, losing their ability to work, to love and play. Thus, you don’t deal primarily with the event of the patient's life or death, you deal with the content of his life when you talk with him about his death. Through the growing relationship between patient and doctor, the amount of truth can increase until, **with the advance of disease, of pain and debility, the loss of life itself is not a significant experience, because there is not that much life left to live.** People define life in terms of what they do, and so the doctor's active partici-
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professor Koenig, does a man have the right to know that he is now about to die, that his death is proximate?

PROFESSOR KOENIG: I don’t know why the question ever comes up, that one might not have the right to know what his situation is. Nowhere else in the relationship between people is the institutionalization of this kind of deception-by-default accepted as a healthy and appropriate part of a relationship, professional or personal. If I went to my financial counselor, and he didn’t want to tell me that Chrysler was going to drop 10 points because it might upset me, I would dismiss him. If I went to my doctor, and he didn’t feel that I was sufficiently integritous as a human being to deal with reality, I would dismiss him. In point of fact, when you obscure reality as a physician, and walk out of the room as you suggested, the distasteful feeling that’s in your mouth hasn’t come from breathing the same air as a dying patient is breathing, it’s come from the sense that you failed to deal honestly and integritously with another human being, who needs to be treated with respect and can only be respected by being treated with honesty. I don’t mean that the doctor who comes in and speaks straight from the shoulder and says, “Well, I’m going to lay it on the line,” is on the right track, because in doing that, he may be attempting to dismiss the patient who presents an uncomfortable conflict for him.

There is no way to anticipate what a patient wants to know without asking. You simply have to say, “What do you think is the matter with you?”, and get his definition of his illness. Begin with him, understand what he feels, what
he suspects, and from that, piece by piece, put together the puzzle. **In time, he will have a clear and true perception of his real situation, doing it sensibly, perceptively, patiently but always honestly.**

**DR. KINGMA:** Freud once said that in the unconscious, every one of us is convinced of his own immortality. I think the implication here is that we are not prepared to handle information like “You are dying.” What about that, Dr. von Brauchitsch?

**DR. VON BRAUCHITSCH:** I wish everything was as easy and straightforward as Professor Koenig would have us believe, that there can be mature dialogue between the doctor and the patient, everything on an adult level, everything logical, with complete emotional control on both sides. Well, reality isn’t like that. **As a patient lies dying, his mental apparatus undergoes changes** which can be fairly well defined. There are two phases, and in the first phase, all psychological entities are mobilized. The patient very strongly reaches out for interpersonal relations. There is a survival reaction, an attempt to mobilize all the resources to win the fight. This is a most difficult phase as far as patient management is concerned, because the demands on interpersonal relations, on physicians, on nurses are enormous.

At this point, the patient is caught in a **triangle of emotional needs** which are basically incompatible with each other. The first major need he has is denial, denial of the critical nature of his illness. Second, he has a need for dependency; he has to establish a dependent relationship so that he can say at the emotional level, you are the Father, I am the Child, SAVE ME!

The third emotion, the one which we usually try to suppress the most, is rage. The dying patient is a hostile patient. There is an overwhelming rage. Why me? Why not somebody else?

The physician’s role in dealing with this emotional triangle is to balance the three components so that the patient does not have to revert to a single one to the detriment of the other two. The physician ought to encourage the patient to verbalize his needs, to verbalize his feelings rather than to act them out. It is well-known how much a dying patient can act out his hostility or his dependency or his denial.

And so, by encouraging the patient to ventilate his feelings, and by very judiciously juggling one emotional need against the other, re-enforcing one here, helping to repress another there, we can establish in the patient an emotional equilibrium. It may not be entirely reality-oriented, not entirely mature, but at least it allows the patient to be as happy as he can under those circumstances.

**DR. KINGMA:** Father Wollard, what kind of support can you offer a patient who is nearing his death?

**FATHER WOLLARD:** Some of the support that is needed and that we can offer is called for by a rather basic problem. Few people in our society have seen another human being die, and therefore, when confronted by death, the primary mode in which they function is their imagination of what death may be like. This has at least two momentous effects on the dying patient. First, those who normally sup-
port him, his family and friends, may at the time of approaching death find that they are unable to deal with the situation, and flee. And there are always good and reasonable excuses for leaving. Thus, the loneliness, anticipated and so feared by the patient, becomes a reality.

Pressures on the hospital staff do not help the problem much either. For it is much more reasonable to spend time with patients who may get well because of invested time and effort, than it is to sit beside one for whom all hope of healing or life is gone. That's the kind of decision that we make almost unconsciously. If two patients press the buzzer at the same time, one who is dying and one who is getting well, there is very little question as to who will get the first response, unless we stop and think for a minute.

And so when the family, the friends and even the hospital staff desert, loneliness is inescapable in the hospital setting. Extra effort, extra support is required to see that this isolation does not occur (unless the patient really wants to be alone).

Second, our society's lack of experience with death means that the dying patient doesn't know whether he is doing well or badly in the death process. Now that may sound a little strange, that somebody at the point of death would still have a little of this thing left called pride, but I believe that does occur. Indeed, he may actually be looking for some reassurance that he is doing something well. If possible, most people would like to carry out even their dying well, and all they have to judge their efforts by is the response of those around them. For this reason, it can be very supportive to have the staff, or the chaplain, or almost anyone in the hospital community, occasionally say, out loud, "You are a very good patient; you are doing a good job." Human presence and the comfort of personal praise are not the only kinds of support that the dying patient requires, obviously. But these are two kinds that can be most easily overlooked.

DR. KINGMA: The relatives of terminal patients need a lot of guidance too. Dr. O'Bryan, how can we help them better?

DR. O'BRYAN: Life and the interpersonal relationships with family become very precious at this time, and this is the time when the family's griefs and frustrations can become vocal or even threatening. To avoid problems with families, it's important to get families to understand the goals of treatment and to keep them informed about the course of the illness and about the kinds of therapeutic approaches that are being attempted. This helps the family understand that the patient has not been abandoned and that they as a family are doing all they can. It also helps the family realize that the purpose of our treating a dying patient is not simply to prolong life and certainly not to prolong suffering. Communication with disjointed families can be quite difficult; the family unit is not always a family unit. Here again we see a whole range of responses. We are all familiar with the typical Aunt Alice who flies in from Baltimore, sees Cousin Charlie on his death bed, and says, "How come nobody's doing anything for Cousin
Charlie; who's in charge here?" At the other end of the range, Aunt Alice comes in, sees poor Cousin Charlie lying there in the bed, and her reaction is, "Well, that dirty rascal was never any good any way." These are the ranges that we work with.

**Helping Our Patients to Die**

*DR. KINGMA:* The third major area that we want to get into is this: assuring that our patient may die with dignity. Our society is very concerned these days about the quality of life and it is only very recently that it is starting to be concerned about the quality of dying. How can we help our patients die? There is a subtle shift in the importance of aspects of our patient's care which occur when a patient is actually dying; the proportion shifts away from the technical and medical, into those aspects which can best be defined as interhuman relationships.

**PROFESSOR KOENIG:** The most universal reaction among nursing personnel (and less publically, physicians) is a sense of hopelessness, a feeling that my hands are tied, that there is nothing I can do. And I suppose that this shift in orientation towards a humane type of relationship is as much a bastion for the staff against this sense of hopelessness, as it is a support for the patient against the hopelessness of nonexistence.

For the staff, a good death is probably a serene, quiet and peaceful death. But this isn't consistent with a man who may not have lived a quiet or peaceful life. He may choose to go out screaming, and if that's his choice, I think we should respect him and respect it, and recognize that he is accepting his death in a way that is appropriate for him to accept it. Accepting death or accepting fatal illnesses is not sitting back and relaxing in the face of this inexorable force that's consuming you. Acceptance can only be defined on the basis of whether the patient does the things that he needs to do to get the treatments that he requires. He does his part only in being a patient, and being a good patient simply means being consistent as he has always been.

I guess probably the most important thing for hospital staff to do is to talk to patients without undue concern about whether they are saying the right thing, or whether the issues are too volatile. Just go ahead and talk. You can't make such a big mistake as you might expect you can.

*DR. KINGMA:* Dr. O'Bryan, what medical help can we offer the patient who is agitated or in severe pain?

*DR. O'BRYAN:* Cancer is a chronic illness and most of the pains associated with cancer are chronic pains. Chronic pain is more difficult to control than acute pain, and the principle we follow is to get the pain controlled early in the treatment. If this takes high doses of narcotics, if it takes surgical or radiologic procedures, so be it. After that we can taper the doses of the narcotic or other analgesic to tolerance. We have found that this approach, rather than a slow build-up in dosage, works much better in terms of control and also in terms of total narcotic use. It is also obvious that the calm patient is
far more comfortable with less analgesics than the agitated patient; and the best tranquility is imparted by human kindness and attention to the total patient needs. This can be coupled occasionally with good doses of various pharmacologic agents for tranquilization.

**DR. KINGMA:** Dr. von Brauchitsch, the ability to communicate with a dying patient often breaks down towards the end. Why is this?

**DR. VON BRAUCHITSCH:** You see me shake my head in reaction to some comments. As beautiful as it sounds to talk about the pride, the dignity, the serenity of the dying patient, the grim reality is that maybe only one in a thousand patients truly have these qualities. Good clinical investigations recently published consistently show that in terminal illness there is this second phase, a total, organic systems breakdown, part of which is an acute psychotic, and that most patients die psychotic. Most patients, if not all, in days or in weeks preceding their death, will have severe impairment of their spacial-temporal orientation. They will have impairment of memory, attention and recall. At least half, and possibly all of them, will hallucinate and have delusions. At that stage, talk about rational, logical communication with a patient doesn’t make much sense.

This doesn’t mean that the human element has to be excluded. You can help a psychotic patient a great deal, but only if he knows you. At that time, to enter the picture as a consultant and as a stranger, you are useless. If you have been a stranger to the patient throughout his illness, you will be a stranger to him at the time of his dying. Only the familiar face and the constant, reliable, day-to-day contact on an emotional level can help the patient and give him reassurance.

**DR. KINGMA:** Father Wollard, you get this thrown at you quite often. “The man is dying. The man is dead. Take care of the relatives, will you?”

**FATHER WOLLARD:** In the hospital, the job isn’t quite over when the patient has expired. We still have the business of dealing with the family and, in many instances, the hospital simply re-enforces our cultural lack of experience with human death. Most often at the moment of a patient’s death, the family is unceremoniously removed from the room and left to their own devices, or to the chaplain, or to the ward clerk, until they can be rounded up and told that the patient has died. Therefore, in addition to the shock of losing a member of the family, there is the added problem of a certain air of unreality. Did it really happen? All this is perhaps momentary, but it does add to the difficulty.

What do you say to this family whose response may range anywhere from stupefaction to rage? Are there any good answers to the questions the family ask? The inevitable one—Why? Or, would it have helped if we had gotten him here sooner? Are there really any answers to these? I think not. Most of these questions are emotional responses in a highly emotional situation, and we answer them much more by the tone we use, by the evidences of concern we have given, than any specific words or ideas could ever manage. It’s all too easy again to flee
such situations as this, but in this, as with the patient, it is the human response to human emotion that is important. At any rate, we have the difficult problem of dealing with families for only the first short portion of their grief process. Sedatives, of course, have their place in loss of control in the family, but certainly not in every case. Simple venting is the most useful griefing mechanism for most people; time and renewed perspective are the only ultimate source of comfort.

**DR. KINGMA:** Well, that's all we have time for. In closing, let me reiterate that our patients and their relatives are people living through a time of anxiety and crisis. For all of them, our supreme act of kindness is to maintain open and dependable and continuing communication, a right they are too often denied. Mr. Jack Mendelsohn, of the Arlington Street Church in Boston, has phrased it so well:

“For those of us who are given the awesome privilege of being near to others as their dying comes, the offerings that count are love, honor, dignity and faithfulness. But these are strange forces. They cannot be handed to others as gifts. They can only be LIVED towards others.”

**REFERENCES**