

BY ELISABETH KÜBLER-ROSS

Questions and Answers on Death and Dying

To Live Until We Say Good-Bye

Living with Death and Dying

Remember the Secret

Death: The Final Stage of Growth

On Children and Death

Working It Through

AIDS: The Ultimate Challenge

On Death and Dying

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Some Interviews with Terminally Ill Patients

Death, thy servant, is at my door. He has crossed the unknown sea and brought thy call to my home.

The night is dark and my heart is fearful—yet I will take up the lamp, open my gates and bow to him my welcome. It is thy messenger who stands at my door.

I will worship him with folded hands, and with tears. I will worship him placing at his feet the treasure of my heart.

He will go back with his errand done, leaving a dark shadow on my morning; and in my desolate home only my forlorn self will remain as my last offering to thee.

Tagore, from *Gitanjali*, LXXXVI

IN PREVIOUS chapters we have tried to outline the reasons for the increasing difficulties patients have in communicating their needs at the time of serious or perhaps fatal illness. We have summarized some of our findings and attempted to describe the methods used to elicit the patient's awareness, problems, concerns, and wishes. It seems helpful to include more random examples of such interviews as they give a better picture of the variety of responses and reactions demonstrated by both the patient and the interviewer. It should be remembered that the patient rarely knew the interviewer; both had met only for a few minutes in order to arrange for the interview.

I have selected one interview of a patient whose mother was visiting at the same time and who volunteered to meet with us in order to share her responses. I think they demonstrate well how different members of a family cope with terminal illness and how, at times, both members have completely different recollections of the same event. Each interview is followed by a brief summary relating the material to statements made in earlier chapters. These original interviews will speak for themselves. They were purposely left unedited and unabbreviated and demonstrate moments when we were perceptive of a patient's implicit or explicit communications and times when we did not react in the most responsive manner. The part that cannot be shared with the reader is the experience that one has during such a dialogue: the many nonverbal communications that go on constantly between patient and physician, physician and chaplain, or patient and chaplain; the sighs, wet eyes, the smiles, gestures with the hands, the empty look, the astonished glance, or the outstretched hands—all communications of significance which often go beyond words.

Though the following interviews were, with a few exceptions, the first meetings we had with these patients, they were in most cases not the only ones. All patients were seen as often as indicated until they died. Many of our patients were able to be discharged home once more, either to die there or to be readmitted to the hospital later on. They asked to be called once in a while when at home, or they called one of the interviewers "to keep in touch." It happened occasionally that a relative would drop in at our office for an informal visit either to gain some insight into a patient's behavior and ask for help and understanding, or to share some memories with us later after the patient's death. We tried to remain as available to them as we were to the patient during hospitalization and thereafter.

The following interviews may be studied in regard to the role the relatives played during these difficult times.

Mrs. S. had been deserted by her husband, who was only indirectly informed by their two small boys of her fatal illness. It was a neighbor and friend who played the most significant role

during her terminal illness though she expected her estranged husband and his second wife to take care of her children after her death.

The seventeen-year-old girl demonstrates the courage of a young person in facing such a crisis. Her interview is followed by one with her mother; both of them speak for themselves.

Mrs. C. felt unable to face her own death because of the many family obligations she had to fulfill. Here again is a good example of the importance of family counseling when sick, dependent, or old people have to be taken care of by the patient.

Mrs. L., who had been the eyes for her visually handicapped husband, uses this role to prove that she can still function, and both husband and wife use partial denial in the time of their crisis.

Mrs. S. was a forty-eight-year old, Protestant woman, mother of two young boys whom she raised alone. She had expressed a wish to talk to someone and we invited her to come to our seminar. She was reluctant and somewhat anxious about coming, but felt greatly relieved after the seminar. On the way to the interviewing room she talked casually about her two boys, and it seemed obvious that they were her biggest concern during this hospitalization.

DOCTOR: Mrs. S., we really know nothing about you except for the minute, you know, we talked with you before. How old are you?

PATIENT: Let's see. Sunday I'll be forty-eight.

DOCTOR: This coming? I'll have to think of it. This is the second time you have been in the hospital? When did you come in the first time?

PATIENT: In April.

DOCTOR: What did you come in for?

PATIENT: This tumor, on my chest.

DOCTOR: What kind of a tumor?

PATIENT: Well, now that I really can't tell you. You see, I don't know enough about this disease to know one kind from another.

DOCTOR: What do you think it is? How were you told what you have?

PATIENT: Well, you see when I went to the hospital they took a biopsy, and then about two days later my family doctor came in and said that the results came back and that it was malignant. But actually the name of what kind it was I don't—

DOCTOR: But they told you it was malignant.

PATIENT: Yes.

DOCTOR: When was that?

PATIENT: That was in, oh, that must have been in the last part of March.

DOCTOR: Of this year? So until this year you were healthy?

PATIENT: No, no. You see, I have an arrested case of TB, so I have spent months in the sanitarium, at one time or another.

DOCTOR: I see. Where, in Colorado? Where did you go to the sanitarium?

PATIENT: In Illinois.

DOCTOR: So, you have had a lot of illness in your life.

PATIENT: Yes.

DOCTOR: Are you kind of almost used to hospitals?

PATIENT: No. I don't think you ever get used to them.

DOCTOR: And then, how did this illness start? What brought you to the hospital? Can you tell us about the beginning of this illness?

PATIENT: I had this little lump. It was like, oh, like maybe a blackhead or something, you know. Right here. And it kept getting larger, and painful and, ah, I don't think I'm any different than anyone else, I didn't want to go to a doctor and kept putting it off, until finally I realized it was getting worse and worse and I had to go and see someone. Well, a few months before that my family doctor that I've had for years passed away. And I didn't know who to go to. Naturally, I mean, I don't have a husband, I was married for twenty-two years and my husband decided there was someone else he wanted. So it was just the boys and I, and I felt that they needed me. I think probably that's one reason why I thought that if there was something very serious the matter, why, well, I kept saying it just couldn't be. I have to be home with the boys. That was the main reason that I put it off. Well, and then when I did go it was getting very large and so painful I

couldn't stand it, stand the pain any longer. And when I went to the family doctor, why, he just said that he couldn't do anything there in the office. I would have to go to the hospital. And so, I went. I think four or five days later I was admitted to the hospital and— I also had a tumor on one ovary.

DOCTOR: At the same time? This was found?

PATIENT: Yes. And I think he intended to do something about that also while I was there, and then when he took the biopsy of this and he came back, it was a malignant one and naturally he wouldn't do anything else. And so he said he could do nothing more for me there, I would have to make up my mind where I wanted to go.

DOCTOR: Meaning to which hospital?

PATIENT: Yes.

DOCTOR: And then you picked this hospital?

PATIENT: Yes.

DOCTOR: How come you picked this hospital?

PATIENT: Well, we have a friend who was a patient here at one time. I know him through my insurance, and he couldn't speak high enough of it and the doctors and the nurses. He said the doctors are specialists and you'll get wonderful care.

DOCTOR: Are you?

PATIENT: Yes.

DOCTOR: I'd be curious how you took this, when it was told to you that you had a malignancy. How did you take it after postponing, postponing to hear the truth. Or to hear the fact, you know, out of your needs to be home and take care of your children. How did you take it when it finally had to be said?

PATIENT: When I first heard it I went all to pieces.

DOCTOR: How?

PATIENT: Emotionally.

DOCTOR: Depressed, crying?

PATIENT: Ah ha. I always thought that I couldn't have anything like that. Then when I realized how serious it was I thought it's something I have to accept, going all to pieces will solve nothing, and I suppose the sooner I can go to someone who can help me the better it will be.

DOCTOR: Did you share this with your children?

PATIENT: Yes. I told them both. I mean, ah, I don't know really how much they really do understand. I mean they know it's something that's very serious but as far as how much they understand I don't know.

CHAPLAIN: How about the rest of your family. Did you share this with any others? Do you have any others?

PATIENT: I have a fellow, a friend that I've been going with for about five years. He's a very nice person and he has been very good to me. And he's been good to the boys, I mean, since I've had to be away from the boys he has been overseeing them, seeing that someone was there with them to get their meals at night, to be with them. I mean that they aren't entirely alone, you know, entirely on their own. Of course, the older boy, probably he would be responsible enough but he is still a minor, I feel, until he is twenty-one.

CHAPLAIN: You feel more comfortable with somebody there.

PATIENT: Yes. And then I have a neighbor there. It's more like a duplex, she lives in the other half of the house. And she's in and out every day. And she's been helping me with my housework at home, between those two months that I was home. She took care of me, you know, she'd give me my baths and see that I had a meal to eat. She's a very wonderful person. She's a very religious person, you know, in her own faith, and she has done just an awful lot for me.

DOCTOR: What faith does she have?

PATIENT: I don't know whether I really know what church she does go to.

CHAPLAIN: Protestant?

PATIENT: Yes.

CHAPLAIN: Do you have other family or is this—

PATIENT: I have a brother who lives here.

CHAPLAIN: But he's not as close as—

PATIENT: We haven't been too close, no. I feel that in the short time that I've known her, she's really the closest one I have. I mean, I can talk to her and she talks to me, which makes me feel better.

DOCTOR: Um hm. You are lucky.

PATIENT: She's wonderful. I've just never known anyone like her.

Nearly every day I get a card or a few lines in the mail from her. It might be silly, it might be serious, but, I mean, I even look forward to just hearing from her.

DOCTOR: Just that somebody cares.

PATIENT: Yes.

DOCTOR: How long ago did your husband leave you?

PATIENT: In September of '59.

DOCTOR: '59. Then did you have tuberculosis?

PATIENT: The first time was in 1946. I lost my little girl. She was two and a half years old. And at that time my husband was in the service. She got very sick and we took her to a specialist in the hospital. And, ah, the hardest thing was that I couldn't see her while she was there. And she went into a coma and she never did come out of it. They asked if it would be all right to perform an autopsy, and I said yes, perhaps it might help someone else someday. So they performed an autopsy, and she had what they call military TB. That was in the bloodstream. And when my husband went in the service, my father came to live with me. And so afterward we all had checkups and my father had quite a large cavity in one lung, and I had just a small amount of trouble. So he and I both went into the sanitarium at that time. And I was there about three months, the only medication I had to have was bedrest and shots. I didn't have to have any surgery. And then, well, on through the years, I was there before and after each one of the boys was born. And I haven't been there now as a patient since after the youngest boy was born in '53.

DOCTOR: Your girl was your first child?

PATIENT: Yes.

DOCTOR: And the only girl you had. That must have been quite something. How did you recover from that?

PATIENT: Well, it was very hard.

DOCTOR: What gave you strength?

PATIENT: Prayer, probably, more than anything. She and I were, I mean, she was all I had for all that time. She was three months old when my husband left. She was just, well, I really lived for her, you know. And I didn't think I could accept but I did.

DOCTOR: And now since your husband left it's the boys that you live for.

PATIENT: Yes.

DOCTOR: That must make it very hard. And now does your religion or prayers or what help you to take care of all the times when you have the blues or you feel depressed about your illness?

PATIENT: Prayers I think are the main thing.

DOCTOR: Do you ever think or talk with anybody in terms of how it's going to be if you would die of this disease or— You don't think about these things?

PATIENT: Well, ah, I haven't too much, no. Other than this lady friend of mine, she will talk with me you know about how serious it is and things that, ah, other than her I haven't talked with anyone.

CHAPLAIN: Does your priest come to see you or do you attend church?

PATIENT: Well, I did go to church before. You know, I hadn't been feeling well for months, even before I came in here. And I hadn't been too good at going to church. But—

CHAPLAIN: Does the priest come to see you?

PATIENT: The priest came to see me when I was in the hospital there at home before I came here. And he was coming down to see me again before I came in, and I guess I just all of a sudden decided to come here, so he didn't get to see me before I came. And then after I was here for about two or three weeks, Father D. came to see me.

CHAPLAIN: Primarily, though, your faith has been nourished by your own private resources at home. Where you haven't had an outlet talking to anyone at church.

PATIENT: No.

CHAPLAIN: But your friend has played this role.

DOCTOR: You sounded like this friend was a relatively new friend.

Did you just move into this duplex or did she just move in?

PATIENT: I've known her for about, oh, maybe a year and a half.

DOCTOR: Is that all? Isn't that wonderful. How did you click in such a short time?

PATIENT: Well, I don't know. It's really rather hard to explain. I

mean she said all her life she always wanted a sister and in talking I said why I always wanted a sister too. I said there were just the two of us, my brother and I, and she said, well, I think we've found each other and I think you have a sister now and so do I. Just to have her walk in the room, she makes you feel, oh, you just feel good like it's home.

DOCTOR: Did you ever have a sister?

PATIENT: No. Just my brother and I.

DOCTOR: You had just one brother. What kind of parents did you have?

PATIENT: Well, my father and mother were divorced when we were very small.

DOCTOR: How small?

PATIENT: I was two and a half and my brother was about three and a half. And we were raised by an aunt and uncle.

DOCTOR: How were they?

PATIENT: They were very wonderful to us.

DOCTOR: Who are your real parents?

PATIENT: My mother is still living. She lives here and my father passed away not too long after he had been sick and been in the sanatorium.

DOCTOR: Your father died of his tuberculosis?

PATIENT: Yes.

DOCTOR: I see. Whom did you feel closer to?

PATIENT: Well, I mean, like my aunt and uncle, they were really my father and mother. I mean, we were with them from the time we were little. And, I mean, they never, they told us they were an aunt and uncle, but I mean they were like parents to us. DOCTOR: There's nothing phony about it. They were honest about it.

PATIENT: Yes, yes.

CHAPLAIN: Are they living?

PATIENT: No. My uncle has been dead for several years. My aunt is still living. She is eighty-five years old.

CHAPLAIN: Does she know about your illness?

PATIENT: Yes.

CHAPLAIN: Do you have much contact with her?

PATIENT: Well, yes I do. I mean she doesn't get out too much, she's not too well. Last year she had arthritis of the spine and she was in the hospital for quite some time. I didn't know whether she would be able to live through that illness or not. She did, and she is doing quite well now. She has her own little place, she lives by herself, takes care of herself which I think is wonderful.

DOCTOR: Eighty-four?

PATIENT: Eighty-five.

DOCTOR: How do you make your living? Were you working?

PATIENT: I worked part-time up until the time I came in here.

DOCTOR: In April?

PATIENT: Yes. But my husband gives us so much a week support

DOCTOR: I see. So you are not dependent on working?

PATIENT: No.

DOCTOR: Your husband has still some contact with you?

PATIENT: Well, he, he sees the boys whenever he wants to and that's always—I always felt whenever he wanted to see them that it was up to him. He lives in the same town as I do.

DOCTOR: Um hm. Is he married again?

PATIENT: Yes, he's married. He was remarried, oh, perhaps a year or so after he left.

DOCTOR: Does he know about your illness?

PATIENT: Yes.

DOCTOR: How much does he know?

PATIENT: Ah, I don't know really, I mean, nothing but perhaps what the boys have told him.

DOCTOR: You don't verbally communicate with him.

PATIENT: No.

DOCTOR: I see. You haven't seen him then personally?

PATIENT: Not to talk to him. I don't—no.

DOCTOR: What kind of parts of your body are involved now with this malignancy?

PATIENT: Well, it's this tumor here and this spot on the liver. And then I had this large tumor on my leg that had eaten most of the bone away and so they inserted that pin in my leg.

DOCTOR: That was in the spring or summer?

PATIENT: In July. And then I also have that tumor on my ovary which is questionable—though you see they have as yet to find out where it started.

DOCTOR: Yes. They know it's in different places now but they don't know where the original came from. Yes. What's the worse part about having such a malignancy for you? How much does it interfere with your normal life and activities? You can't walk, for example, can you?

PATIENT: No. Only with crutches.

DOCTOR: You can walk around in the house with crutches?

PATIENT: Yes. But as far as doing, say your cooking and your housework, you are very limited.

DOCTOR: What else does it do to you?

PATIENT: Well, I really don't know.

DOCTOR: I thought you said upstairs that you had lots of pain.

PATIENT: I do.

DOCTOR: Yes. Do you still have that?

PATIENT: Um hm. I think after so many months you rather learn to live with it, I mean, when it gets so bad you can't stand it and you ask for something. But I never was one that cared to take any medicine.

DOCTOR: Mrs. S. impresses me as one who will take a lot of pain, until she says something. Like she waits a long time and sees the tumor grow before she sees the doctor.

PATIENT: That's always been my biggest trouble.

DOCTOR: Are you difficult for the nurses? Do you tell them when you need something? What kind of a patient are you, do you know?

PATIENT: I think you had better ask the nurses that. (Jokingly)

CHAPLAIN: Oh, that's easy, but we are interested in how you feel.

PATIENT: Oh, I don't know. I, I think I can get along with anyone.

DOCTOR: Ah ha. I think so. But maybe you don't ask enough.

PATIENT: I don't ask any more than I have to.

DOCTOR: How come?

PATIENT: I really don't know. I mean, different people are different. You see, I always was happy when I could take care of myself, do my own housework, and do things for the boys. That is what bothers me the most. That I feel that someone

else has to take care of me now. That is very hard for me to accept.

DOCTOR: Is getting more sick the worst part of it? Would be not being able to give to others?

PATIENT: Yes.

DOCTOR: How else could you give to others without being physically active?

PATIENT: Well, you can remember them in your prayers.

DOCTOR: Or what you are doing here right now?

PATIENT: Yes.

DOCTOR: Do you think that's going to help some other patient?

PATIENT: Yes. I think it does. I hope it does.

DOCTOR: How else do you think we can be of help? How is dying for you? What does it mean to you?

PATIENT: I'm not afraid to die.

DOCTOR: No?

PATIENT: No.

DOCTOR: It has no bad connotations?

PATIENT: I don't mean that. Naturally everyone wants to live as long as they can.

DOCTOR: Naturally.

PATIENT: But I wouldn't be afraid of dying.

DOCTOR: How do you conceive of it?

CHAPLAIN: This is what I wondered, not that we are communicating anything to you except that people do have problems. Do you think of what will happen if this leads to death? Have you thought about this? You mentioned talking to your friend.

PATIENT: Yes. We have talked about it.

CHAPLAIN: Could you share some of your feelings about this?

PATIENT: It's sort of hard for me to, you know, talk . . .

CHAPLAIN: It's more comfortable to talk with her about it than with someone else.

PATIENT: To someone else you know.

CHAPLAIN: Could I ask you a related question, in terms of how has your illness, and this is the second illness for you, you've had tuberculosis, and you've lost your daughter—how have these experiences affected your attitude toward life, your religious thoughts?

PATIENT: I guess it has brought me closer to God.

CHAPLAIN: In what way? In feeling that he could be of help, or—
 PATIENT: Yes. I just feel that I have put myself in his hands. It would be up to him if I could get well again—lead a normal life.

CHAPLAIN: You mentioned difficulty in being dependent on other people, and yet you are able to find a good deal of help from this friend of yours. Is it difficult to depend on God?

PATIENT: No.

CHAPLAIN: He's more like this friend, eh?

PATIENT: Yes.

DOCTOR: But if I understood right, your friend has the same needs that you have. She also needs a sister, so it's a give and take, it's not just a taking.

PATIENT: She's had sorrow and difficulties in her life, perhaps that has brought her closer to me.

DOCTOR: Is she a lonely woman?

PATIENT: She can understand. She's a married woman, she never had any children, she loves children, she has never had any of her own. But she loves everyone else. She and her husband have work there at the children's home, they've been house parents. Oh, they always have children around them all the time, and they have been very nice to my boys too.

DOCTOR: Who takes care of both of them if you should be in a hospital for a long time, or if you should die?

PATIENT: Well, ah, I think it would be natural if anything happened to me that their father would. It would just be his place to—

DOCTOR: How do you feel about that?

PATIENT: I think that would be the best thing.

DOCTOR: For the boys.

PATIENT: I don't know if it would be the best thing for the boys, but—

DOCTOR: How do they get along with his second wife? Who would really be their substitute mother?

PATIENT: Well, they really have no use for her.

DOCTOR: In what way?

PATIENT: Well, I don't know whether she resents the boys, or I don't know. But I do think, in his heart, that their father loves the boys, I think he always has. If it came down to it I don't know if there is anything he wouldn't do for them.

CHAPLAIN: Your boys are pretty far along. The younger one is thirteen?

PATIENT: Thirteen. He is in the eighth grade this year.

DOCTOR: Thirteen and eighteen, eh?

PATIENT: The oldest boy graduated from high school last year. He was just eighteen in September. So he had to sign up for the draft, which doesn't make him too happy, which doesn't make me happy either. I don't think about that. I try not to but then I do.

DOCTOR: Especially at times like this I think it is very difficult to think about. Has the hospital as a whole, and individuals on your floor been helpful in every way they could or do you have any suggestions how things could be improved for patients like you, who have, I'm sure, a lot of problems and conflicts and worries, and very hardly talk about it, like you.

PATIENT: Oh, I think, I feel that, I wish that my doctors could explain a little more to me. I realize, I mean I still feel like I'm in the dark, as far as really knowing about. Well, now maybe there are some people who want to know how sick they are and some people that don't. Well, if I thought that I just had a short time to live I would want to know that.

DOCTOR: Did you ask him?

PATIENT: No. But the doctors are always in a hurry—

DOCTOR: Will you please grab him the next time and ask him?

PATIENT: I feel that their time is valuable. I mean I don't—

CHAPLAIN: This isn't too different than what she said about her other relationships. She doesn't impose on anybody and to take somebody's time is sort of an imposition unless she is going to feel comfortable with them.

DOCTOR: Unless the tumor gets so big, and the pain so unbearable that you can't take it anymore—right? Who is the doctor you would like to hear from? Do you have several doctors? With whom do you feel more comfortable?

PATIENT: I have so much confidence in Dr. Q., it seems like when he walks in the room, I just, I feel that anything he tells me is, well, it's all right.

DOCTOR: Maybe he waits for an opening to be asked?

PATIENT: I've always felt that way toward him.

DOCTOR: Do you think it's possible that he waits for an opening to be asked from you?

PATIENT: Well, I don't know, I don't— He probably tells me what he thinks is necessary.

DOCTOR: But it's not enough for you.

CHAPLAIN: Well, she states this in terms of wanting to be told more. The examples she gives was, well, if I'm going to have a short time to live, which raised the question in my mind as to whether this is something that you are concerned about? Is this the way you are phrasing it in your own mind?

DOCTOR: What is a short time to live, Mrs. S.? That's terribly relative.

PATIENT: Oh, I don't know. I would say six months or a year.

CHAPLAIN: Did you feel as strongly about knowing if it weren't that kind of condition? I mean that's the illustration you used.

PATIENT: Whatever I have I have, and I would still want to know. I mean, there are some people I think you could tell and there are other people that you couldn't.

DOCTOR: What would change?

PATIENT: Oh, I don't know. Maybe I'd just try to enjoy each day a little bit more if I—

DOCTOR: You know no doctor can tell you the time. You know, he doesn't know— But some doctors mean well and give an approximate estimation, and some patients get terribly depressed and don't enjoy a single day after that. What do you say to that?

PATIENT: It wouldn't bother me.

DOCTOR: But you understand why some doctors are very leery.

PATIENT: Yes. I'm sure there are people who'd go and jump out a window or—do something drastic.

DOCTOR: Some people are like this, yes. But you have apparently thought about this for a long time, because you know where

you stand. I think you should talk to the doctor, you should tell him. Just open the door and see how far you can get.

PATIENT: Maybe he doesn't think I should know just what I have, I mean that's—

CHAPLAIN: You'd find out.

DOCTOR: You always have to ask and then you get the answer.

PATIENT: My first doctor that I knew when I came in here, you know the first time when I came in to the clinic for my first checkup, I just had so much confidence in him, from the first day that I saw him.

CHAPLAIN: That's, I think, a justified confidence.

DOCTOR: That's very important.

PATIENT: I mean, I get home, you have your family doctor, you feel you are quite close to him.

DOCTOR: And then you lost him too.

PATIENT: And that was very hard because he was such a wonderful man. He had so much to live for. He was just, he was in his late fifties. And of course, as you know, a doctor's life isn't an easy life. And I think that he probably just didn't take care of himself like he should have. His patients came first.

DOCTOR: Like you! Your boys came first—

PATIENT: They always did.

DOCTOR: Was this so difficult now? You know, you came here kind of leery. Here to the conference.

PATIENT: Well, I didn't really feel too enthusiastic about coming. DOCTOR: I know.

PATIENT: But then I thought, well, I just made up my mind I would.

CHAPLAIN: How do you feel about it now?

PATIENT: I'm glad I came.

DOCTOR: It wasn't so terrible, was it? You know you said you are not a good speaker. I think you did a very good job.

CHAPLAIN: Yes, I am that. I was wondering, though, if you had any questions to ask us—catching the cue earlier that doctors don't slow down long enough to get the patient to ask a question. We are slowing down enough to where if you have any questions to ask us about the session, anything—

PATIENT: Oh, I mean, I, when you came and when you mentioned that, I just didn't quite understand what it would solve or what it would—what was the main idea, you know.

CHAPLAIN: Has this been answered in part, by the conference?
PATIENT: Partially, yes.

DOCTOR: You see, what we are trying to do is to learn from the patient really, how we can talk to complete strangers we haven't met before, and we haven't known each other at all, how can we get to know a patient, fairly well and pick up what kind of needs and wants he has. Then go about it to serve this, like I learned a lot from you now, that you know fairly well what your illness is, you know it's serious, you know it's in different places. I don't think anybody can tell you how long this is going to be going on. They tried a new diet, which I think they haven't given to many patients, but they have a lot of hopes with this. This I know is an unbearable kind of diet for you. I think everybody tries their best to make it, you know—

PATIENT: If that's what they think will help me then I want to try it.

DOCTOR: They do. That's why they give it to you. But what you are saying, I think, is that you would like to have some time to sit with the doctor and talk about it. Even if he can't give you all the answers all clear and pat; I think nobody can. But just to talk about it. The kind of things you do with your family doctor, the kind of things we are trying to do here.

PATIENT: I don't feel as nervous as I thought I would. I mean I feel quite at ease.

CHAPLAIN: I thought you were very relaxed sitting here.

PATIENT: When I first came in here I was just a little bit jumpy.

CHAPLAIN: You made that comment.

DOCTOR: I think we will take you back then. We'll drop in once in a while. Okay?

PATIENT: Sure.

DOCTOR: Thank you for coming.

In summary, then, we have here a typical example of a patient who has had many losses in her life, who needed to share her

concerns with someone, and who felt relieved to ventilate some of her feelings with someone who cared.

Mrs. S. was two and a half when her parents divorced and she was raised by relatives. Her only daughter died at age two and a half from tuberculosis while her husband was in the service and she had no one else as close as this little girl. Soon afterward she lost her father in the sanatorium and had to be hospitalized herself with tuberculosis. After twenty-two years of marriage her husband left her with two small boys for another woman. A family doctor in whom she had great confidence and trust died when she needed him the most, namely, when she noticed a suspicious lump which later proved to be malignant. Raising the boys alone, she postponed treatment until the pain became unbearable and her malignancy was spread. In all her misery and loneliness she always found some meaningful friends, however, with whom she was able to share her concerns. They too were substitutes—just like her aunt and uncle were substitutes for her real parents; the boy friend replaced the husband, the neighbor substituted for a sister she never had. The latter was the most meaningful relationship as she became a substitute mother for the patient and her children as her illness progressed. This service fulfilled a need of her own and was done in an unintrusive, sensitive manner.

The social worker played a crucial role in the later management of this patient as well as her doctor, who was informed of her wish to share more personal matters with him.

The following is an interview of a seventeen-year-old girl with aplastic anemia, who asked to be seen in the presence of the students. An interview with her mother took place immediately afterwards, followed by a discussion among the medical students, attending physician, and nursing staff of her ward.

DOCTOR: I think I'll make it a little easy on you, okay, and let us know please if you get too tired or are in pain. Do you want to tell the group how long you have been ill and when it all started?

PATIENT: Well, it just came on me.

DOCTOR: And how did it come on?
PATIENT: Well, we were at a church rally in X, a small town from where we live, and I had gone to all the meetings. We had gone over to the school to have dinner and I got my plate and sat down. I got real cold, got the chills and started shaking and got a real sharp pain in my left side. So they took me to the minister's home and put me to bed. The pain kept getting worse and I just kept getting colder and colder. So this minister called his family doctor and he came over and said that I had an appendicitis attack. They took me to the hospital and it seemed like the pain kind of went away; it just kind of disappeared by itself. They took a lot of tests and found that it wasn't my appendix so they sent me home with the rest of the people. Everything was okay for a couple of weeks and I went back to school.

STUDENT: What did you think you had?

PATIENT: Well, I did not know. I went to school for a couple of weeks and then I got real sick one day and fell down the stairs and felt real weak and was blacking out. They called my home doctor and he came and told me that I was anemic. He put me in the hospital and gave me three pints of blood. Then I started getting these pains in here. They were bad and they thought maybe it was my spleen. They were going to take it out. They took a whole bunch of X-rays and everything. I kept having a lot of trouble and they didn't know what to do. Dr. Y. was consulted and I came up here for a checkup and they put me in the hospital for ten days. They ran a whole bunch of tests and that's when they found out that I was aplastic.

STUDENT: When was this?

PATIENT: That was about the middle of May.

DOCTOR: What did this mean to you?

PATIENT: Well, I wanted to be sure it was too, because I was missing so much school. The pain hurt quite a bit and then, you know, just to find out what it was. So I stayed in the hospital for ten days and they ran all kinds of tests and then they told me what I had. They said it was not terrible. They didn't have any idea what had caused it.

DOCTOR: They told you that it was not terrible?

PATIENT: Well, they told my parents. My parents asked me if I wanted to know everything, and I told them yes, I wanted to know everything. So they told me.

STUDENT: How did you take that?

PATIENT: Well, at first I didn't know and then I kind of figured that it was God's purpose that I got sick because it had happened all at once and I had never been sick before. And I figured that it was God's purpose that I got sick and that I was in his care and he would take care of me so I didn't have to worry. And I've just gone on like that ever since and I think that's what kept me alive, knowing that.

STUDENT: Ever get depressed about it?

PATIENT: No.

STUDENT: Do you think others might?

PATIENT: Oh, someone might get real, real sick. I feel that, you know, there's no reassuring thing, but I think everybody who gets sick feels that way once in a while.

STUDENT: Do you wish at times that it was not your parents that had told you about the condition—you wish maybe the doctors had told you about it, had come to you?

PATIENT: No, I like my parents to tell me better. Oh, I guess it was all right that they had told me, but I would have kind of enjoyed that so much . . . if the doctor had shared it with me.*

STUDENT: The people that have been working around you, the doctors, and nurses, do you think they have been avoiding the issue?

PATIENT: They never tell me anything, you know, just mostly my parents. They have to tell me.

STUDENT: Do you think you've changed your feelings about the outcome of this disease since the first time you heard about it?

PATIENT: No, I still feel the same.

STUDENT: Have you thought about it long?

PATIENT: Uh huh.

STUDENT: And this hasn't changed your feelings?

PATIENT: No, I went through the trouble, they can't find veins on me now. They give me so many other things like that with

* Here she expresses her ambivalence about being told by her parents instead of the doctor.

all these other problems, but we just have to keep our faith now.

STUDENT: Do you think you've got more faith during this time.

PATIENT: Uh huh. I really do.

STUDENT: Do you think this would be one way that you've changed? Your faith is the most important thing then that will pull you through?

PATIENT: Well, I don't know. They say that I might not pull through, but if he wants me to be well, I've got to get well.

STUDENT: Has your personality changed, have you noticed any changes each day?

PATIENT: Yes, because I get along with more people. I usually do, though. I go around and visit a few of the patients and help them. I get along with the other roommates, so I get someone else to talk to. You know, when you feel depressed it helps to talk to someone else.

DOCTOR: Do you get depressed often? Two of you were in this room before, now you are all alone?

PATIENT: I think it was because I was worn out. I haven't been outdoors for a week now.

DOCTOR: Are you getting tired now? Tell me when you get too tired, then we will finish this session.

PATIENT: No, not at all.

STUDENT: Have you noticed any change in your family or friends, in their attitude toward you?

PATIENT: I've been a lot closer to my family. We get along well, my brother and I were always close when we were small. You know he's eighteen and I'm seventeen, just fourteen months apart. And my sister and I were always real close. So now they and my parents are a lot closer. You know, I can talk to them more and they, oh, I don't know, it's just a feeling of more closeness.

STUDENT: It's deepened, enriched your relationship with your parents?

PATIENT: Uh huh, and with other kids, too.

STUDENT: Is this a sense of support for you during this illness?

PATIENT: Yes, I don't think I could go through it now without my family and all the friends.

STUDENT: They want to help you in every way possible. How about you, do you help them, too, in some way?

PATIENT: Well, I try to . . . whenever they come I try to make them feel at home and make them go home feeling better and things like that.

STUDENT: Do you feel very depressed when you're alone?

PATIENT: Yes, I kind of panic because I like people and I like to be around people and being with someone . . . I don't know, when I'm alone all the problems come up. Sometimes you do feel more depressed when there's nobody there to talk to.

STUDENT: Is there anything in particular that you feel when you're alone, anything that sort of scares you about being alone?

PATIENT: No, I just get to feeling that there's nobody there and nobody to talk to.

DOCTOR: Before you were sick, what kind of girl were you? Were you very outgoing or did you like to be alone?

PATIENT: Well, I was pretty outgoing. I liked to do sporty things, go places, go to games and to a lot of meetings.

DOCTOR: Have you ever been alone for any length of time before you were sick?

PATIENT: No.

STUDENT: If you had to do it over again, would you rather your parents had waited before telling you?

PATIENT: No, I'm glad I knew right from the start. I mean I'd rather know right at the beginning and know that I have to die and they can face me.

STUDENT: What is it that you do have to face, what's your vision of what death is like?

PATIENT: Well, I think it's wonderful because you go to your home, your other one, near to God, and I'm not afraid to die.

DOCTOR: Do you have a visual picture of this "other home," realizing, you know, all of us have some fantasies about it though we never talk about it. Do you mind talking about it?

PATIENT: Well, I just kind of think it's like a reunion where everybody is there and it is real nice and where there's someone else there—special, you know. Kind of makes the whole thing different.

DOCTOR: Is there anything else you can say about it, how it feels?

PATIENT: Oh, you would say you have a wonderful feeling, no more needs and just being there and never again alone.

DOCTOR: Everything just right?

PATIENT: Just right, uh huh.

DOCTOR: No need for food to stay strong?

PATIENT: No, I don't think so. You'll have a strength within you. DOCTOR: You don't need all these earthly things?

PATIENT: No.

DOCTOR: I see. Well, how did you get this strength, all this courage to face it right from the beginning? You know many people have a religion, but very few at the time will just face it like you. Have you always been that way?

PATIENT: Uh huh.

DOCTOR: You never had any real deep hostile—

PATIENT: No.

DOCTOR: Or got angry at people who weren't sick.

PATIENT: No, I think I got along with my parents because they were missionaries for two years in S.

DOCTOR: I see.

PATIENT: And they've both been wonderful workers of the church. They just brought us all up in a Christian home and that has helped a great deal.

DOCTOR: Do you think we, as physicians, should speak to people who face a fatal illness about their future? Can you tell us what you would teach us if your mission was to teach us what we should do for other people?

PATIENT: Well, a doctor will just come in and look you over and tell you "How are you today" or something like that, a real phoney. It just kind of makes you resent being sick because they never speak to you. Or they come in like they are a different kind of people. Most of the ones I know do that. Well, they come down and talk with me for a little while and ask me how I feel and visit with me. They say things about my hair and that I'm looking better. They just talk to you and then they'll ask you how you feel and some get into explaining things as much as they can. It's kind of hard for them because I'm underage and they aren't supposed to tell me anything, be-

cause they are supposed to tell my parents. I think that's so important to talk to a patient because if there's a cold feeling between the doctors you kind of dread to have them come in if he's going to be cold and businesslike. When he comes in and is warm and human that means a great deal.

DOCTOR: Did you have a feeling of discomfort or unpleasantness about coming here and talking about it to us?

PATIENT: No, I don't mind talking about it.

STUDENT: How have the nurses handled this problem?

PATIENT: Most of them have been real wonderful and talk a great deal and I know most of them pretty well.

DOCTOR: You have the feeling that the nurses are able to handle it better than the physicians in a way?

PATIENT: Well, yes, because they are there more and they do more than the doctors.

DOCTOR: Uh huh, they just may be less uncomfortable.

PATIENT: I'm sure of that.

STUDENT: May I ask, has anybody in your family ever died since you grew up?

PATIENT: Yes, my dad's brother, my uncle died. I went to his funeral.

STUDENT: How did you feel?

PATIENT: Well, I don't know. He looked kind of funny, he looked different. But, you know that's the first person that I'd ever seen dead.

DOCTOR: How old were you?

PATIENT: I'd say about twelve or thirteen.

DOCTOR: You said "he looked funny" and you smiled.

PATIENT: Well, he did look different, you know, his hands didn't have any color and they did look so still. And then my grandmother died but I wasn't there. My grandfather died on my mother's side, but I wasn't there either, I just went on, you know. Oh, then my aunt died and I couldn't go to the funeral because it was not too long ago and I was sick and we didn't go.

DOCTOR: It comes in different forms and ways, doesn't it?

PATIENT: Yes, he was my favorite uncle. You don't really have to

cry when somebody dies because you know they're going to heaven and it's kind of a happy feeling for them, to know that they're going to be in paradise.

DOCTOR: Did any of them talk about it to you at all?

PATIENT: A real, real close friend of mine just died, over a month ago and his wife and I went to his funeral. That meant a lot to me because he had been so wonderful and had done so much for me when I got sick. He left you feeling so comfortable and everything.

DOCTOR: So what you say is to be a little more understanding and take a little time and talk with the patients.

The interview with this young girl's mother follows. We talked with her soon after interviewing her daughter.

DOCTOR: We have a very few parents who are coming to us to talk about their very sick children and I know this setup is kind of unusual.

MOTHER: Well, I asked for it.

DOCTOR: What we talked about with your daughter is how she feels and how she looks at death. We were impressed by her calmness and lack of anxiety as long as she is not alone.

MOTHER: She talked much today?

DOCTOR: Yes.

MOTHER: She's in a great deal of pain today and feels very, very bad.

DOCTOR: She talked a lot, much much more than this morning.

MOTHER: Oh, and I was afraid she'd get in here without saying anything.

DOCTOR: We're not keeping you for long, but I would appreciate it if you would allow the young doctors to ask you a few questions.

STUDENT: When you first found out about your daughter's condition, that it was not curable, how did you react to this?

MOTHER: Well, very well.

STUDENT: You and your husband?

MOTHER: My husband wasn't with me at the time and I felt a

little bad at the way I found out. We just knew that she was sick, but that was all and so then when I came down to visit her that day, I called to see how she was. The doctor said, "Oh, she's not at all good. I have some bad news for you." He showed me the way to one of the little rooms and he just, quite frankly, said, "Well, she has aplastic anemia and she's not going to get well, that's all." He said, "Nothing can be done, we don't know the cause, we don't know the cure." And so I said, "Well, can I ask you a question?" And he said, "If you want to." I said, "How long does she have, doctor, maybe a year?" "Oh, no, goodness no." And I said, "For this, we're lucky." And that's all he said and so then I had a lot of other questions.

DOCTOR: This was last May?

MOTHER: May, the 26th, uh huh. And he said, "There's a lot of people who have it, it's incurable and that's all there is to it. She'll just have to accept it." And he walked out. I had a hard time finding my way back to her ward and I guess I got lost in one of the halls, trying to go back I got panicky. All the time I just stood there and I thought, "Gee, it means she's not going to live," and I was all wrong and I didn't know how to get back to her. Then I pulled myself together and went back and talked with her. I was afraid at first to go in and tell her how sick she was because I didn't know how I felt and I might go in crying. So I straightened myself up before I went to see her again. But it was quite a shock the way it was presented to me and the fact that I was alone. If he had had me sit down at least and tell me, I think I could have accepted it a little better.

STUDENT: Exactly how did you wish that he would have presented it to you?

MOTHER: Well, if he had waited—my husband was with me every other time and this was the first time I was alone, and if he had called us both in and maybe said, "Well, she has this incurable disease." He could have told it to us frankly, but had a little bit of compassion and needn't seem so hard-hearted. I mean, how he put it, "Well, you're not the only one in the world."

DOCTOR: You know, I've run up against this many times and it hurts. Has it occurred to you that this man might have some

difficulties about his own feelings in regard to such situations?

MOTHER: Yes, I've thought this, but it hurts anyway.

DOCTOR: Sometimes the only way they are able to communicate such news is in a cool, detached way.

MOTHER: You're right, too. A doctor can't get emotional about these things and probably should not. But I don't know, there must be better ways.

STUDENT: Have your feelings toward your daughter changed?

MOTHER: No, I'm just real thankful for each day that I have with her, but I hope and pray for a lot more, which isn't right, I know. But no, she was raised with the idea that death can be beautiful and it is nothing to worry about. I know she will be as brave when it happens. Just once have I seen her break down and cry to me, when she said, "Mother, you look worried," and she said, "Don't be worried, I'm not afraid." She said, "My God's waiting for me, he'll take care of me so don't you be afraid." She said, "I'm a little bit afraid, does that bother you?" I said, "No, I think everybody is." I said, "But you just keep up the way you are," I said, "Do you feel like crying? Go ahead and cry, everyone does." She said, "No, there's nothing to cry about." So I mean she had accepted it and we had accepted it, too.

DOCTOR: That was ten months ago, wasn't it?

MOTHER: Yes.

DOCTOR: A very short time ago you had also been given just "twenty-four hours."

MOTHER: Last Thursday the doctor said we were lucky if it was twelve to twenty-four hours. He wanted to give her some morphine to shorten it and make her less painful. We asked him if we could think about it for a minute and he said, "I don't see why you just don't do it and stop the pain." He walked away. We decided therefore it would be better for her to let him go ahead and do it. And so we told the floor doctor that he could tell him that we agreed. We never have seen him since and they have never given her the shot. Then she has had good days and she has real bad ones, but she is slowly getting more of it and she is needing all the things that I have been told that would happen from other patients.

DOCTOR: Where from?

MOTHER: Well, my mother is from P., there are two hundred of these patients and my mother has learned a lot about them. She said towards the end they get so that it hurts to even touch them and it hurts all over. Then she says, even to lift them, their bones break. Now she hasn't wanted to eat for a week or so and all these things begin to happen. Up until the 1st of March, you know, she used to chase the nurses up and down the hall and help them and take water to the other patients, cheer them up.

DOCTOR: So the last month has been the hardest.

STUDENT: Has this changed your relationship with your other children at all?

MOTHER: Oh, no, they used to quarrel all the time and she would quarrel and then she used to say, "Oh, I just hope that this will make it easier." They still quarrel a little bit, but I don't think that they quarrel any more than any other and they never hated each other, but (chuckles) they have been real nice to children.

STUDENT: How do they feel about it themselves?

MOTHER: Oh, they purposely don't baby her. They treat her just like they did before. That is good because it doesn't make her feel sorry for herself and they talk back to her a little bit and so forth. If they have other things to do well they tell her, "I'm not coming to see you this Saturday, I'll be down during the week instead. You understand me, don't you?" And she'd say, "Yeah, have fun." And she'll go along with the idea and each time they come they know that she probably won't be coming home, you know. So they realize and we leave word where we can be reached and get in touch with one another.

DOCTOR: Do you talk with your other children about this possible outcome?

MOTHER: Oh, yes.

DOCTOR: You talk about it open and frankly?

MOTHER: Yes, we do. We have been sort of a religious family. We have devotions every morning, pray before they go to school and I think this has been a great help to them because as a family, especially with teen-agers they've always got some-

place to go, something to do and we can't seem to get together to sit down and talk over problems and things like that, but they will take this time each morning and bring in family problems. We get things ironed out in these ten or fifteen minutes each morning and it brings us all together. We have talked about it quite a bit and in fact our daughter has made arrangements for her own funeral already.

DOCTOR: Do you want to tell us about that?

MOTHER: Yes, we talked about it. There was a little baby born in our community—in our church, in fact, who is blind. I think she's about six months old and one day my daughter up in the old hospital said, "Mother, I'd like to give my eyes to her when I die." And I said, "Well, we'll see what we can do about that, I don't know if they would take them." I said, "You know we really should talk about things like that, all of us should, because we never know when Daddy and I may be on the road and something may happen to us and you children will be left alone." And she said, "Yes, we should have all these things agreed upon." And she said, "Let's you and I now make it easy for the others. We'll write down what we would like to have done and we'll ask them what they would like to have done." So she made it easy for me and she said, "I'll start and then you tell me." So I just jotted down things that she told me and it made it much easier. But she always does try to make things easy for people.

STUDENT: Did you have any suspicion at all before you were told that it might be an incurable illness? You said your husband had been with you all the other times, this particular time you happened to be alone. Was there any particular reason why he wasn't there?

MOTHER: I try to go to the hospital as much as I can and he was ill. And he has more free time than I ordinarily would. So he was with me most of the time.

STUDENT: Your daughter told us he had been a missionary in S. and you're very active in church work. This was part of the reason for the deep religious background. What was the nature of his missionary work? Why isn't he still in it?

MOTHER: Well, he was a Mormon. And they always paid all his

funds, paid all his benefits and everything, and so when we were first married, I went along to church for about a year. Then he started going with me and for seventeen years he went every Sunday with me and the children. About four or five years ago he joined our church and has been a worker—has been in it all that time.

STUDENT: I was wondering since your daughter does have a disease for which the cause and cure are not known, if you've never felt kind of an irrational feeling of guilt?

MOTHER: Yes, we have. Many times we've probed into the fact that I never have given them vitamins. My family doctor kept saying they didn't need it and I kept saying maybe they have, have been taking them, and then I tried to pin it down to all kinds of things. She had an accident back East. They say that could cause it because of the bone. They say any injury to the bone can cause this. But the doctors here say, "No, it would not—it had to be within a few months before." She has had a great deal of pain but she bears up under it so well. No, we always pray "Thy will be done" and we feel that if he wants to take her, he will and if not he'll perform a miracle. But we've almost half given up for a miracle, but they say never give up. We know that the best will be done. And we have asked her—this is another thing. They told us never to tell her. She had a great deal of growing up to do this last year. She's been in with all kinds of women, one who tried to commit suicide, and women who talked about their problems with their husbands and having babies. There isn't a thing she doesn't know and people she hasn't come in contact with. And she's had a great deal to put up with. The one thing she does not like is people trying to hide things from her. She wants to know about everything. So we told her. We talked it over and then when she was so terribly sick last week and we thought that this was the end. The doctor was telling us in the hall about this and she immediately asked, "What did he say, am I going to die now?" And I said, "Well, we're not sure. He said you're very bad." And so she said, "Well, what does he want to give me?" I never did tell her what, I said, "It's a pain-killer." She said, "Is it dope, I don't want any dope." I said, "It

would help your pain." And she said, "No, I would rather suffer through. I don't want to become a dope addict." I said, "You won't." And she said, "Mother, I'm just amazed at you." And she never did give up, just always keeps on hoping that she will get well.

DOCTOR: Do you want to finish this interview? We have only a few minutes left. Do you want to tell the group how you feel about the hospital treating you as the mother of a dying child. You want to be with her naturally as much as you possibly can. How much help have you gotten?

MOTHER: Well, it was very nice back in the old hospital. They were very friendly; they are much busier in the new one and the service isn't quite as good. They always make me feel like I'm in the way when I'm here, the resident doctor and the intern especially. I'm just in their way. I even get where I hide out down the hall and try to sneak past him. I feel like a thief coming in and going out because they look at me as if to say, "Are you here again?" They just brush past me, you know, don't talk to me. I feel like I'm invading on something, like I shouldn't be here. But I do want to stay here, and the only reason I stay is because my child asked me to and she's never asked me to before. And I try to stay out of the way. In fact, I don't mean to be conceited, but I think I've helped a lot. They are very short-handed and I know the first two or three nights she was so bad, I don't know what she would have done because the nurses would avoid her and the older lady in the same room. The older lady had a heart attack and cannot even get on a bedpan and I had to help put her on some nights and my daughter would be throwing up and she needed to be washed and cared for and they just wouldn't do it. Somebody has to do it.

STUDENT: Where do you sleep?

MOTHER: In the chair right there. The first night I didn't have a pillow or a blanket or anything. One of the other patients who doesn't sleep with a pillow insisted that I take her pillow and I covered myself with my coat and then the next day I began bringing my own in. I guess I shouldn't tell it, but one of the janitors (chuckles) brings me a cup of coffee now and then.

DOCTOR: Good for him.

MOTHER: I feel like I shouldn't say all this, but I have to get it off my chest.

DOCTOR: I think these things should be brought out. It is important to think about these things and talk about it, not beat around the bush and say everything is fine.

MOTHER: No, as I was saying, the attitude of the doctors and nurses makes such a difference with the patients and family.

DOCTOR: I should hope you had some good experiences, too.

MOTHER: I should say. There's a girl who works at nighttime and they have been taking things and several of the patients complained and nothing was done about it. She is still on the job and so these patients now lay awake at night waiting for her to come in the room because they are afraid of these things being stolen. And when she does come, she's very rude, you know, and extremely mean, and she's a maid. And then the next night a nice, tall colored boy came in to our door and he said, "Good evening. I'm here to make your night more cheerful," and his whole attitude was great. All night long he came when I pushed the bell. He was just wonderful. And the next morning both patients in the room were one hundred percent better and this makes the day so much better.

DOCTOR: Thank you, Mrs. M.

MOTHER: I hope I didn't talk too much.

Following is the interview with Mrs. C., who felt that she could not face her own death because of the pressure of family obligations.

DOCTOR: You said you had so many things that go through your head when you lay in bed alone and think. And so we offered to sit together for a while and just listen. One of your big questions involved your children. Is that correct?

PATIENT: Yes, my biggest concern is my little daughter. I also have three sons.

DOCTOR: They are almost grown up, though, aren't they?

PATIENT: Yes, but I know that children react to very sick parents,

especially when it is the mother. You know that these things do have quite a bearing in childhood. I wonder what this might do to her when she grows up like this. When she grows up and looks back at those things.

DOCTOR: What kind of things?

PATIENT: Well, first the fact that her mother has become inactive. Much more inactive than she has ever been before, both in school and church activities. And I am more afraid now of who is taking care of my family. More afraid than when I was at home, even when I was inactive at home. A lot of times it is not known among the friends and nobody wants to talk about it. So I told others, I thought people should know it. And then I wonder if I did the right thing? I wonder if whether I did the right thing in letting my girl know that young, or whether it should have been postponed until later?

DOCTOR: How did you tell her?

PATIENT: Well, children are quite outright in the questions they ask. I was perfectly frank in the way I answered her. But I did it with feelings. I have always had a feeling of hope. A feeling of hope that they might discover something new any day and I still might have a chance. I was not afraid and I feel that she should not be afraid. If the disease ever progressed to a state of hopelessness, that I could not function any more and that I would become too uncomfortable, I was not afraid to still go on. I hope that she was developing and maturing through Sunday school work. If I only knew that she could go on and that she did not feel it was a tragedy. I never, never wanted her to feel that way. I just don't feel that way and that's how I talked with her. Many times I tried to be cheerful with her and she always thinks they are going to fix me up in here. And this time again, she thinks they are going to fix me up in here!

DOCTOR: You still have some hope but certainly not as much as your family has. Is this what you are saying? And it may be the difference of awareness that makes it more difficult.

PATIENT: Nobody knows how long this can still last. I surely have always held on to hope, but this is the lowest I have ever been. The doctors have not revealed anything to me. They have not told me what they have found during the operation. But any-

body would know without being told. My weight is down to the lowest it has ever been. My appetite is very poor. They say I have an infection that they have not been able to discover— When you have leukemia, the worst thing that can happen to you is to get an infection on top of it.

DOCTOR: You were upset yesterday when I came to visit you. You had a colon X-ray and you felt like giving somebody a piece of your mind.

PATIENT: Right. You know it is not the big things that count when you are so sick and so weak. It is the little things that count. Why in the world can't they talk with me? Why can't they tell you before they do certain procedures? Why don't they let you go to the bathroom before they take you out of the room like a thing, not like a person?

DOCTOR: What really upset you that much yesterday morning?

PATIENT: It is really very personal, but I just have to tell you. Why don't they supply you with an extra pair of pajamas when you go for this colon X-ray? When you get done you are in an absolute mess. Then you are supposed to sit in a chair and you just don't have any desire to sit in that chair. You know it's going to be a mass of white chalk when you get up, and it's an uncomfortable situation. I thought, well, they are so wonderful to me upstairs there in my room but when they send me down here to X-ray I feel like a number or something, you know. They do these strange things to you and it is very uncomfortable to come back in that state. I don't know how this happens but it seems to happen all the time. I don't think it should happen. I think they should tell you ahead of time. I was very weak and very tired. The nurse that brought me up here thought I could walk and I said, "Well, if you think I can walk I can try." By the time I had all my X-rays and climbing up on the table and everything, I was so weak and tired, I wasn't quite sure I could reach my room.

DOCTOR: That must make you feel angry and frustrated.

PATIENT: I don't get angry too often. I suppose the last time I can remember being angry was when my older son went out and my husband was working. There was no way to lock the house, and, of course, I didn't feel safe to go to sleep with the house unlocked. We are right on the corner. There is a street

light on the corner, and I couldn't fall asleep until I knew the house was locked. I had talked to him so much about this and he has been pretty good about calling and letting me know but this night he didn't.

DOCTOR: Your oldest son is a problem child, isn't he? You mentioned yesterday briefly that he has been emotionally disturbed and retarded too, isn't he?

PATIENT: Correct. He has been in a state hospital for four years. DOCTOR: And he is back home now?

PATIENT: He is home.

DOCTOR: Do you feel that there should be more control over him, and you are a bit worried that he doesn't have enough control, like you over the unlocked house that night?

PATIENT: That is correct, and I feel that I'm the one that's responsible—so much responsible and I can do so little now.

DOCTOR: What happens when you cannot be responsible anymore?

PATIENT: Well, we are hoping that maybe this will open his eyes a little wider because he cannot understand things. He has a lot of good in him but he needs help. He could never manage on his own.

DOCTOR: Who would help him?

PATIENT: Well, there is the problem.

DOCTOR: Can you speculate, do you have people in your house who would help out?

PATIENT: Well, of course, as long as my husband is living he could look after him. But it is a concern because he has to be away from home so many hours working. We have the grandparents there but even then I feel that is altogether unsatisfactory.

DOCTOR: Whose parents?

PATIENT: My husband's father and my mother.

DOCTOR: Are they in good health?

PATIENT: No, they are not in good health. My mother has Parkinson's disease and my father-in-law has a bad heart condition.

DOCTOR: All this in addition to your concerns about your twelve-year-old girl? You have your older son and he is a problem.

You have your mother with Parkinson's, who will probably start shaking when she tries to help somebody. Then you have a father on your husband's side who has a heart condition and you are not well. Somebody should be at home to take care of all those people. This I think is what bothers you most.

PATIENT: Right. We try to make friends and hope that the situation would be taken care of. We live from day to day. Each day seems to be taking care of itself, but as far as looking ahead, you cannot help but wonder. You know, with me having this illness on top of everything else. You never know if you should just try to be wise and accepting the situation calmly from day to day or if you should make a drastic change.

DOCTOR: Change?

PATIENT: Yes, there has been a time when my husband said, "a change has to be made." The old folks have to go. One would have to go to my sister, the other would have to go to a nursing home. You just have to learn to be cold, and put your family in an institution. Even my family doctor thinks I should put my son in an institution. And still I cannot accept these things. In the end I went to them and said, "No, I may feel worse if you leave, so you stay. And if it ever has to be, if it does not work out, you just come back again. If you went away it would be worse." I had advised them to come in the first place.

DOCTOR: You would feel guilty if they went to a nursing home?

PATIENT: Well, I would not if it got to the point where it was dangerous for them to go up and down stairs or—I do feel it's getting a little dangerous for my mother around the stove now.

DOCTOR: You have been so used to taking care of other people, it must be tough for you to be taken care of now yourself.

PATIENT: It's a bit of a problem. I have a mother who tries to help me, a mother who is more interested in her children than anything else in the world. That is not always the best thing too, because you should have other interests, you know. She has been entirely interested in her family. That's her life, sewing and doing little things for my sister who lives next door. I'm glad of that because my daughter can go over there. And

I'm very happy that my sister lives next door. So my mother goes over there and this is good for her too because it makes a little change for her.

DOCTOR: It makes it easier for everybody. Mrs. C., can you tell us a little more about you. You said that this time you feel the weakest, that you have lost the most weight. When you are in bed, you know, lying there alone, what kind of things do you think about and what helps you most?

PATIENT: Well, coming from the kind of family that I came from and my husband came from, we knew that if we started our marriage we had to have an outer strength besides ourselves. He was a Boy Scout leader and there had been marital problems between his father and mother who eventually separated. This was the second marriage for my father, he had three children. He married a very young waitress and that didn't work out at all. It was really pitiful, these little children were divided around, you know. They didn't come to live with my mother when he married my mother. My father was a very temperamental person, a very high-strung man with not a good disposition. And now I often wonder how did I cope with it. And so when we lived in that area my husband and I met each other in church. We were married. And we knew that to make our marriage we had to have outside strength. We've always felt that way. We've always been active in church work and I started teaching Sunday school when I was sixteen years old. They needed help in the nursery so I did it and I enjoyed it. I taught up until I had the two older boys. I enjoyed it and I often gave devotions in my church and told them what my church meant to me. What my God meant to me, so I think you just don't throw that all overboard when something happens. You go on believing, you know that whatever happens, will happen.

DOCTOR: That's something that helps you now too?

PATIENT: Yes. And when my husband and I talk we know we both feel the same way. As I told Chaplain C., we know that we could never be tired with other people talking about it. I told him also our love is as strong now after twenty-nine years

of marriage as it was when we were married. This is another thing that means a lot to me. We have been able, with all our problems, to face them. He's a wonderful man, a very wonderful man!

DOCTOR: You dealt with your problems courageously and well, the hardest perhaps being your son?

PATIENT: We did the best we could. I don't think it's just an opportunity for any parent. You just don't know how to quite deal with it. You think it's stubbornness at first, you just don't know.

DOCTOR: How old was he when you noticed that he had a problem?

PATIENT: Well, you find it quite obvious. They don't ride a triangle and do not do all the other things that children do. But actually, a mother doesn't want to accept these things. She will find other explanations at first.

DOCTOR: How long did it take you?

PATIENT: Up to my age, but actually when he got into school, into kindergarten, he was a problem to the teacher. He often stuck something into his mouth to attract attention. I began to get reports from the teacher, then I knew definitely that we had a problem with him.

DOCTOR: So you accepted the full facts step by step just as you did with the diagnosis of leukemia. What kind of people in the hospital help you the most with your daily problems?

PATIENT: Every time you run across a nurse who expresses faith, it's a big help. As I say, when I went down to that X-ray yesterday I felt just sort of like a number, you know, and there wasn't anybody who cared very much, especially when I went down the second time. It was late and they were disturbed that they would send a patient down there that late. So they were disturbed all the way around. I knew when she brought me, she was going to put that wheelchair there and disappear, and I'd sit there until someone came out. But one of the girls there told her she shouldn't do that, she should go in and tell them I was there and have them come out. I think she was upset having to go that late with a patient. They were closing

up, the technicians were going home and it was late. Little things like this, you know, the cheerfulness of the nurses would help so much.

DOCTOR: What do you think of people who have no faith?

PATIENT: Well, I run across that, too. I run across that with patients here, too. There was a gentleman who was here last time and when he found out what I had he said, "I can't understand, nothing fair in this world, why should you have leukemia, you've never smoked, you never drank, you never did anything like that," you know. He said, "Me, I'm an old man, I did a lot of things I never should have done." It doesn't make any difference. We are not told that we will never have any problems. Our Lord himself had terrific problems to face, so he's the one who teaches us and I am trying to follow him.

DOCTOR: Do you ever think about dying?

PATIENT: Do I think about it?

DOCTOR: Yes.

PATIENT: Yes, I do. I oftentimes think about dying. I don't like the idea of everybody coming to see me because I look so awful. Why does that have to happen? Why can't they just have a little memorial service? You know, I don't like the idea of funerals, you know, maybe that's strange. I just have a repulsion, my body in that casket.

DOCTOR: I am not sure I understand.

PATIENT: I don't like to make people unhappy, like my children, by two or three days of this sort of thing, you know. I thought about that and have done nothing about it. My husband asked me one day when he came in; he said, shall we actually look into this, donating our eyes or donating our bodies? We didn't do it that day, and we still haven't done it because it's one of those things you put off, you know.

DOCTOR: Do you ever talk with anybody about it? Kind of preparing yourself for that time whenever it comes?

PATIENT: Well, as I told Chaplain C., I think for many people there is such a need to lean on somebody, to talk to the chaplain and they want all the answers from him.

DOCTOR: And does he give them the answers?

PATIENT: I think if you understand Christianity, by the time you

reach my age you should be mature enough to know that you can reach out and have this yourself because you are going to be by yourself a great many hours. You are alone in illness, because people just can't be with you all the time. You can't have the chaplain with you, you can't have your husband with you, you can't have people with you. My husband is the kind of person who would be with me as much as he could.

DOCTOR: It helps then most to have people with you?

PATIENT: Oh, yes, especially certain people.

DOCTOR: Who are the certain people? You mentioned the chaplain, your husband.

PATIENT: Yes. I enjoy having my pastor coming to visit with me, from my church. There was another young friend of mine about the same age as I am and she's a very fine Christian. She has lost the sight of her eyes. She was in the hospital for several months flat on her back. She accepted it very well. She is the type of person that is forever doing something for somebody else. If they are ill she is visiting them, or she is collecting clothes for the poor or something like that. She wrote me a nice letter the other day and she quoted the 139th Psalm and I really enjoyed getting that. She said, "I wanted you to know you are one of my closest friends." So you look for a person like that and it makes you happy. It's the little things that make you happy. As a whole I think they are very friendly here now. I think I'm a little bit tired, though, about hearing people suffer in the rooms. I hear this and I think, oh, why can't they do something for that person, you know. It's been going on for a long time and you hear them crying out and you fear that maybe they are alone. You have no right to go to their room and talk to them, you just *hear* them, you know.

This sort of thing bothers me. The first time I was here I couldn't sleep too well and I thought about it. I thought, well, this can't go on. You're just going to have to get your sleep. So I slept quite well. But I heard two patients crying out that night. It is a thing I hope that I never do. I had a cousin who had cancer not long ago and she was older than I. She was a very wonderful person. She was crippled from birth but she handled it just beautifully. She was in the hospital for a great

many months, she never cried out. The last time I visited her was a week before she died. She was a real inspiration. She really was because she was more concerned about me for making the trip over to see her than she was about herself.

DOCTOR: That's the kind of woman you would like to be, hm?

PATIENT: Well, she helped me. I hope I can do it.

DOCTOR: I am sure you can. You have been doing it right here today.

PATIENT: I have one more thing that worries me—one never knows when they get in an unconscious state like that how they are going to react. Sometimes they react differently. I guess it is important that you have confidence in your doctor then, that he can stay with you. Dr. E. is very busy so you just don't talk much with him. Unless he would ask you, you wouldn't bring up a lot of family problems or anything, although I have always felt how much of a bearing do these things have on my health. You know very well that problems can have quite a bearing on your physical health.

CHAPLAIN: That's what you implied the other day that you wondered if the pressures of your family and all the problems there affected your health too.

PATIENT: Yes, because it is true, our son was very bad at Christmas and in fact his dad took him back to the state hospital. He volunteered to go. He said "I'll pack when we get home from church." Then he got down there and changed his mind and came home. His dad said he told him he wanted to go back home, so he took him home. Usually when this boy comes home this boy will pace back and forth. He can't even sit he is so restless sometimes.

DOCTOR: How old is he?

PATIENT: He's twenty-two. It's okay if you can cope with it and do something about it but when you cannot give him his answers or help him it is a terrific thing, just to talk to him. Not long ago I tried to explain what had happened when he was born and he seemed to understand. I said, "You have an illness like I have an illness and you have the roughest time sometimes. I know you have a terrifically rough time and I know how hard it is for you. In fact I give you a lot of credit for

coming out of these rough times and settling down again," you know, and going on. I think he tried harder too, but you really have a mental condition there that you never quite know actually what to do about.

CHAPLAIN: This has been a tension for you. It must tire you, I'm sure.

PATIENT: That's right. I'm sure he's been my biggest problem.

DOCTOR: Your father's first wife had little children and they were kind of distributed and now you have the same question yourself. What is going to happen to them?

PATIENT: My biggest conflict is how can I keep them together, how can I keep from sending them to all sorts of institutions! Well, naturally I feel it will work out. If a person really becomes bedridden then you have an entirely different problem. I may become bedridden again and I say to my husband this will work itself out as the years went by but that hasn't happened. My father-in-law had a very serious heart attack and actually we didn't think he'd do as well as he has. It has been amazing. But he is happy and yet sometimes I wonder if he wouldn't be happier in a situation with other old gentlemen the same age.

DOCTOR: Then you could send him to a nursing home?

PATIENT: Yes, it would not be as hard as he thinks it would be. But he is so proud of being with his son and his wife. He was raised in the town and was in the town all his life.

CHAPLAIN: How old is he?

PATIENT: He is eighty-one.

DOCTOR: He is eighty-one and your mother is seventy-six? Mrs. C., I think we will have to finish because I promised not to make it longer than forty-five minutes. Yesterday you said nobody had talked with you about how your home problems affect you and your thoughts about dying. Do you think this is something that doctors or nurses or anybody else in the hospital should do if the patient so wishes?

PATIENT: It's helpful, very helpful.

DOCTOR: Who should do it?

PATIENT: Well, if you're fortunate enough to have that kind of a doctor, and there are a few, you know, that are going up and

are interested in this side of your life. Most of them are purely interested in the medical part of the patient. Dr. M. is very understanding. He has come to see me twice now since I've been here and I appreciate that.

DOCTOR: Why do you think there is such a reluctance?

PATIENT: Well, it's the same thing on the outside world today. How come we don't have more people doing more things that should be done?

DOCTOR: I think we should finish, don't you? Do you have any questions that you would like to ask us, Mrs. C.? We'll be seeing you again anyway.

PATIENT: No. I only hope to get in front of more and more people and tell them about these things that need help. My boy isn't the only one. There's a lot of people in the world and you just try to have someone interested enough in the case so that possibly they could do something for him.

Mrs. C. is similar to Mrs. S., a middle-aged woman for whom death approaches in the midst of a life of responsibilities, caring for a number of dependent people. She has a father-in-law who is eighty-one and who recently had a heart attack, a mother with Parkinson's disease who is seventy-six, a twelve-year-old girl who still needs her mother and may have to grow up "too quickly" as the patient fears, and a twenty-two-year-old nonfunctioning son who goes in and out of state hospitals, for whom she both fears and cares. Her own father left three small children from a previous marriage and the patient worries that she too has to leave all these dependent people now at a time when they need her the most.

It is understandable that such family burdens make it extremely difficult to die peacefully until these matters are discussed and some solutions found. If such a patient has no opportunity to share her concerns, she is both angry and depressed. Her anger is perhaps best demonstrated in her indignation about the hospital staff member who feels that she can walk to X-ray, who does not take her needs into consideration, and who is more concerned about the end of the working day than the efficient management of a weak, tired patient who likes to function as

long as she can—but not beyond—and who likes to keep her dignity in spite of the unpleasant circumstances.

She describes perhaps best the need for perceptive, understanding people and their influence on the suffering; she sets an example when she allows the old folks to stay at her own home and function as best as they can, rather than sending them off to a nursing home. Also her son, whose presence is barely tolerable but who wishes to stay home rather than to return to the state hospital, is allowed to stay at home and to share as much as he is capable of sharing. In all this struggle to take care of everybody as best as she can, she also communicates the wish to be allowed to stay home and function as long as she can; even if it means being bedridden, her presence there should be tolerated. Her final statement, her wish to get in front of more and more people and let them know the needs of the sick, was perhaps partially fulfilled by this seminar.

Mrs. C. was a patient who wanted to share and accepted help gratefully in contrast to Mrs. L. who accepted the invitation but was unable to share her concerns until much later on, shortly before her death when she asked us to come and visit her.

Mrs. C. continued to do as many things as possible until the question of her emotionally disturbed son was solved. Her understanding husband and her religion helped her and gave her the strength to endure the weeks of suffering. Her last wish, namely, not to be seen "ugly" in the casket, was shared with her husband who understood that Mrs. C. always had a great concern for others. I think this fear of appearing ugly was expressed also in her concerns for the patients she hears crying out loud, "losing their dignity perhaps," and when she fears to lose consciousness and says, "One never knows when they get in an unconscious state . . . how they are going to react . . . It is important that you have confidence in your doctor then, that he can stay with you. . . . Dr. E. is very busy, so you just don't talk much with him. . . ."

This is not so much a concern for others as it is her fear of perhaps losing control, of becoming indignant when the family problems become too overwhelming and her strength too small.

In a subsequent visit she acknowledged the wish to "scream sometimes"—"Please take over, I just cannot worry for everybody