A Father with Leukemia

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This chapter focuses on the impact of an acute fatal illness upon a young married couple. The two authors had the opportunity to follow both the husband and wife closely throughout the ten-week course of this illness, in which we saw not only the personal psychodynamics of the husband and wife, but perhaps more importantly, we were able to observe the longitudinal behavior of the family and hospital staff. This report is an analysis of the relations between all these people in the social network of the dying patient, and the critical role that their communications play in the experience of dying for all concerned.

Mike, 28, and Kathy, 26, had been married fours years and had one son Bob, three. Mike was a professor of music in a local college. He developed leukemia, but its subtype was not known for several weeks. The day that the diagnosis of leukemia was made, treatment with prednisone in high doses was instituted. (Prednisone can produce psychosis.) About 10 days later, Mike developed a manic psychosis. He was hospitalized and treated with lithium and was subsequently followed by one of us. Kathy also sought psychiatric help because she recognized that she was having difficulties coping with Mike's radical personality change as well as her decision whether or not to abort her 12-week pregnancy. Accordingly, she was also followed by a psychiatrist as an outpatient.

The course of Mike's illness from diagnosis to death lasted only 10 weeks. In that interval, many challenges presented themselves: primarily the unpredictability of Mike's behavior and the complexity of the social network including the hospital staff surrounding Mike during the last few weeks of his life.

THE EXPERIENCE OF MIKE

In May, before the end of his teaching year, Mike developed some pain in his joints. His symptoms became so severe that he consulted his physician, who made a diagnosis of rheumatoid arthritis. His physician prescribed phenylbutazone, but that treatment did not relieve the symptoms. About six weeks later, Mike consulted another physician, who discovered a "blood dyscrasia" (imbalance of elements). Mike and Kathy were advised that Mike should go to the University hospital to be evaluated; that his physician did not know what the problem was but thought it "could even be leukemia."

When Mike was admitted to the hospital as an emergency, a bone marrow aspiration was performed immediately. A probable diagnosis of lymphosarcoma

cell leukemia was made. The following day, treatment was started with vincristine and prednisone. Mike's response to these medications was expected to help in establishing his diagnosis and prognosis. His physicians felt fairly certain that he had a highly malignant form of leukemia. Nevertheless, they down-played that. Instead, they stressed the uncertainties involved in establishing the subtype of leukemia. As a result, Mike and Kathy were left to form their own impressions of the seriousness of Mike's illness and of his prognosis. For example, they repeatedly referred to a 38-day trial period for the chemotherapy. The fact that they would know nothing of Mike's prognosis until the end of that time. The uncertainty about Mike's prognosis was very stressful, particularly to Kathy; it was to be a prominent factor in later decisions that she had to make. For example, she was 12 weeks pregnant, and she felt pressured to decide soon whether or not to continue her pregnancy. She was to face that decision alone later; Mike could offer her no support in her decision because of his psychosis.

Before he was discharged from the hospital, Mike was told that he could expect some euphoria as a side effect from his treatment with prednisone. As a result he was not particularly surprised when he began to feel "high" after he returned home. He began to develop an extremely optimistic view toward life in general and, specifically, toward his own life. By his own description he began to see the world in a different light; as if "the windows had been cleaned." He began to experience an increased intensity of the impact of the world on his senses. He described colors as being brighter, aromas stronger, and the experience of living to be much more satisfying.

Mike threw himself into new activities with great vigor, relishing his enhanced awareness of life. One morning he walked to town to have breakfast at a restaurant. For several hours he observed the people around him and speculated at length about their lives. On the way home, he saw some farm workers picketing a local chain grocery store. Mike quickly introduced himself to the farm workers and convinced them that he was very much interested in their cause. He volunteered his services to make some placards for them. Accordingly, he went home and produced a large number of placards in a short period. He even surprised himself at the amount of work he was able to get done so quickly. He said he could not have done it if he had not had such a burst of energy.

Although Mike felt that his newfound energy was a boon to him, his behavior and attitude soon became very alarming to Kathy. As he became more and more active and involved in "living," he became increasingly more egocentric, indulging himself heavily in his own personal productivity. For the next few days, as his activity increased, Kathy felt increasingly more isolated and abandoned. Finally, she convinced Mike to return to the hospital.

After his admission, Mike's mental status was the most prominent part of his clinical picture. He was seen in consultation by a psychiatrist who found him to be highly talkative, extroverted, energetic, and euphoric. He had become

extremely prolific at writing and had taped pages of notes all over his hospital room. His speech was pressured; his verbal output—both written and spoken—was confused and disorganized, characterized by a flight of ideas. He talked of "cosmic consciousness" and feeling "at one with the universe." As to his leukemia, however, he became evasive. He did say that he was quite angry with his first doctor, and made a number of litigation threats against him. He was grandiose and hostile; he was described as "hostile in his friendliness."

The psychiatric consultant felt that Mike might be suffering from manic-depressive illness, but that it was also possible that the mania resulted from an organic brain syndrome secondary to his prednisone treatment. It was recommended that the prednisone be discontinued and that he be observed for changes in mental status. Discontinuation of the prednisone did not result in remission of his mania, so Mike transferred to the psychiatric service.

After admission, Mike remained extroverted and talkative. He slept only one or two hours the first few nights and made many long distance phone calls, running up large bills. He buzzed around the ward continuously, striking up conversations with anyone who was willing and able to listen to him. Despite his sociability, he avoided intimate involvements of any kind, although he was usually drawn to the young women on the ward. His impact on some of the patients was shocking; particularly when he insisted that his leukemia was the biggest miracle of his life.

In addition to socializing, Mike was extremely intent on continuing his writing. He soon assembled the material and personnel necessary to support his prolific efforts. He borrowed a typewriter from a physician on a different ward, he got paper from the nursing staff, and he lined up two patients and a clerk-typist to do his typing for him. During this period, he wrote a song—47 verses of lyrics—and sent it off to a popular folk singer. He also wrote a screen play and a short story, which was a satirical memo written to the staff psychiatrist on the ward. Although it was written in a humorous style, the essay left no doubt about Mike's hostility. In his story, Mike focused all his hostile feelings on to a single psychiatric technician, making that person a scapegoat for a large share of his anger. That was one example of what was to become a pattern of scapegoating in which ultimately Kathy, several physicians, and many nurses were to be involved.

Mike was treated with lithium after admission to the psychiatric ward. The question of how to manage his manic psychosis was made difficult by the fact of his terminal illness. For example, in one sense his mania was useful to him, enhancing his life experience. In that case, it might be preferable to leave it untreated in the short period of time he had to live. On balance, however, Mike's overall pattern of behavior seemed to require specific treatment.

The sense of urgency for the lithium treatment was underlined by several factors involving both Mike and Kathy. In particular, his relationship with Kathy was deteriorating rapidly. Also, Mike was asking for help. He said repeatedly that he

felt out of control and that he would like us to help him gain control of himself. Correspondingly, he was very cooperative with his treatment. He seemed to be aware that he was unable to plan realistically for his own welfare. Our decision to treat Mike's mania, then, was based primarily on our realization that Mike did not live in a vacuum; that his psychosis was actually alienating him from those closest to him—those whom he would need now more than ever. After Mike had been treated with lithium for five days, his serum Lithium level reached therapeutic levels and he calmed down considerably. He was questioned about depression or thoughts of suicide. He was then able realistically to discuss his sadness and fear. However, he had only one brief period of significant depression. That occurred after he was told by his hematologist, Dr. A., not to plan on teaching the autumn semester. Mike called his college to report that he would not be returning to teach and would need a replacement. Then he felt very depressed. He sat in the day room, away from everyone else; he didn't want to speak with anyone and didn't want to be bothered. Later, he went into his room and took a two-hour nap. Afterward, he felt "just fine" again.

Sometimes Mike's sadness was seen when he spoke of his mother's death. On these occasions, he had tears in his eyes; often his voice broke. Mike remembered his mother as a "very warm and bubbly person," in contrast to the cold and aloof person he felt his father to be. Mike's mother had been hospitalized several times for a mental illness that was characterized by periods of "very high highs and very low lows." Her problem was ultimately diagnosed as manic-depressive illness. Mike spoke of his mother's mental illness only once; most of his references to her concerned the family events for the year prior to her death from breast cancer.

Mike's memory of the last year of his mother's life was fixed on their separation. He recalled that she remained in the hospital virtually all the time until just before her death, yet his father indicated that she was actually hospitalized only a few weeks at the beginning and a few weeks toward the end of her illness. In Mike's version of the events surrounding his mother's dying, the whole family was totally unrealistic in approaching it; they denied anything was seriously wrong. Mike remembered that his father refused to discuss with Mike and his brothers the fact that their mother had a fatal illness. Mike's memory of surprise at her death is vivid; he remembered that as he was going home from school one day, some friends asked him about his mother's health. He replied that she was feeling "just fine." That night she died.

Mike said that even after all the intervening years; he had still not gotten over the surprise of his mother's death, and declared that his own impending death would be discussed openly and without denial. In the eight days that he was on the psychiatric unit, he referred repeatedly to what he considered to be the deceitfulness surrounding his mother's death and the openness with which he was approaching his own. Yet his own approach was self-contradictory; while he continued to talk openly about the "miracle" of his leukemia, he tended to depersonalize his disease. Although he made a great effort to remain stoic about

his future, he referred to his impending death as "the death." One time Mike was confronted about "romanticizing" his death. He shrugged off the comment, indicating that it wasn't very important to him one way or the other; that he was willing to go along with whatever fate had in store for him. But if Mike showed a detachment from his own feelings about dying, he appeared to be even less concerned about the feelings of Kathy.

THE EXPERIENCE OF KATHY

The day Mike transferred to the psychiatric unit; Kathy was telephoned because she had previously asked to discuss a possible abortion with a psychiatrist. She had already decided to have an abortion, but she felt that she needed support because of the pressure she experienced. Kathy was seen the following day. She was a well-dressed, petite, and quite attractive young woman. Her initial style persisted throughout this experience. She seemed like a brave little soldier. She relied heavily on her intellect and approached problems with a tough-minded pragmatism. By contrast, she always spoke with a soft trembling voice so that she seemed to be on the verge of tears. But rarely did a tear fall; she never really broke down and cried during our entire contact.

Initially, Kathy gained most of her support from her mother and step-father, with whom she was staying. Her real father did not live far away, but she had not yet contacted him and he did know that Mike had leukemia. She felt rather distant from her real father and felt that she could not rely on him. She said he was a severe alcoholic, and he had never been available to her as a child. She also had a sister in the area, but she did not rely on her sister for support. She explained that her sister had enough emotional problems of her own and that she did not want to trouble her. The desire to protect others from being hurt was a recurring theme with Kathy. She occasionally took this attitude toward Mike in striking contrast to her usual attitude of brave and pragmatic honesty. During the first interview, Kathy said that she felt relatively confident about her decision to go ahead with the abortion and that she felt some urgency in proceeding with it. If she were to wait much longer, a quite complicated procedure would be necessary. There were two things that made her decision to abort very difficult. First, she had no clear idea of what Mike's death trajectory might be. The hematologist, Dr. A., had told them that Mike might live only a couple of months. On the other hand, if he went into a remission there was a fair chance that he might live up to a year or even many years.

Of the possible death trajectories, the one Kathy feared most was one lasting about a year. That would leave her with both an infant and a dying husband to care for at the same time. In that case she would definitely want an abortion. By contrast, if Mike were to live only a few weeks, she would not want to continue the pregnancy. Finally, the third possible—but least likely—death trajectory carried less weight in Kathy's decision-making process; if Mike were to live many years she would want to bear the child; still, even if she had an abortion they

could have another child together later anyway. Kathy's decision to have the abortion, then, was based on the worst possible case; that is, that Mike might live about one year.

A second major problem for Kathy was Mike's reaction to her. Mike was heavily involved in his own personal creativity and not involved in their personal relationship. Kathy said that she wanted to comfort and support Mike during this terrible time, but she herself also wanted some support from him, which she was not getting. She wanted to hear Mike's feelings about how to handle her pregnancy, but he would not talk to her about it. She was worried that he might be very angry at her if she went ahead and aborted because he might see this child as his last link with life.

Kathy was encouraged once again to contact Dr. A., with the hope that she could get a more definitive picture of Mike's probable death trajectory. She called the hematologist several times and left messages for him to return the call; he never did. The abortion was scheduled for a week later. Kathy was seen once again before the abortion. Her difficulty in asserting herself was explored. She expressed some anger at Dr. A. for not returning her calls. She reserved most of her anger for Mike, however. She felt hurt because he seemed unwilling to help her make the decision.

THE MARRIAGE RELATIONSHIP

To improve the understanding and communication between Mike and Kathy, a series of conjoint sessions was initiated with both their therapists. This strategy was adopted because their marriage relationship was in a crisis, and because it was felt that the quality of their relationship prior to the crisis could be reestablished. Ultimately, three conjoint sessions were held. Kathy was to say later that these sessions were the most helpful services provided for her and Mike during his illness.

The first conjoint session centered on the upcoming abortion. Mike superficially agreed to the abortion and glibly stated that he realized it was a tough decision but that he would support whatever decision Kathy made. However, because he was off so quickly to other subjects, Kathy was never sure where he really stood. That session made little progress, primarily because of Mike's flightiness and inability to focus on issues. in this emotional climate, the abortion was performed without any medical complications. The day after the abortion, Kathy reported that she felt well; she would never again mention the abortion to her psychiatrist. Mike, however, did react to it later, even though indirectly. Within the context of his wishes for immortality, Mike indicated that he regretted the necessity for the abortion.

Shortly after the abortion, the second conjoint session was held, during which they both expressed anger toward each other. Kathy was angry at Mike for not

giving her any support and for selfishly pursuing his own creative interests, neglecting the future needs for both her and Bob. Kathy accused Mike of spending money extravagantly. Mike, in turn, was angry at Kathy for ignoring his need to cram a lifetime into a short period. They chose as their battleground the fact that Mike frequently bought boxes of candy for the nurses. They fought long and hard over who was to control the petty cash. Nevertheless, they later realized that the candy was not the issue, and thereby discovered the intensity of the anger they each felt. The main benefit of this session, then, was that they both expressed anger toward one another, and this catharsis seemed to be helpful.

During the third conjoint session, Mike's and Kathy's different perspectives were explored. Mike was more concerned about living for the present; Kathy was primarily concerned about the future. For example, Mike wanted to sell the house so they could have more money to travel and to publish his creative efforts. Kathy wanted to keep the house, so she would have some security for the future. It was pointed out that their differing perspectives were each understandable, but they needed mutual respect for each other's perspective with a willingness to compromise to some extent. They both seemed to understand this, and the relationship between the two of them improved after this session.

Before his condition deteriorated into a semi comatose state, Mike and Kathy had a few good days together. For example, he permitted her to show him sympathy and to perform small comforting tasks that she felt satisfaction in doing. This was a tremendous relief to Kathy. She saw that short period as a warm personal relationship. At this time she decided to compromise and move more toward Mike's perspective. She said that when Mike got out of the hospital she would try to live more for the present and would be quite willing just to travel. And Mike agreed to try to avoid selling the house and to travel by train, instead of by plane, to save money. They were able to share some of their mutual sadness and their concern about Bob.

There was also a psychiatric conference on Mike and the topic of death and dying. Kathy attended this conference. She saw that when Mike was concerned with his own personal productivity and was not giving her love in return, she did not feel like a worthwhile person. She realized that not having love reciprocated need not diminish one's feeling of self-worth. This seemed to help her cope a little better with Mike's occasional angry outbursts at her. She was a little less afraid of his anger and was left feeling less guilty and self-deprecating. Mike also began to reflect on his illness and his reactions to it. For example, he saw the ways in which he was trying to achieve immortality. This was evident in his voluminous writing and his hopes to have his song recorded. It was expressed also in his change of attitude about having children; whereas before he had wanted to have only two children, he had come to the position during his illness that he would like to have "four, five, or maybe even a lot more." Also, he identified an earlier wish of his—to be recorded on video tape—as an attempt to achieve immortality. Mike had requested repeatedly to record an interview about his "philosophy" of

death. He said several times that he hoped to do that so his son would be able some day to "see the old man, and hear what I have to say on life." Mike wished that his mother had left some kind of personal record behind her; particularly, he would like to have heard her talk about her illness. He had accidentally struck her in the breast with a ball prior to her development of breast cancer, and for many years after that, he accepted the blame for her death. Also, Mike's self-selected nickname, "Feather," appeared to be a symbolic indication of his search for immortality. While on an outing, Mike had come across a beautiful feather lying on the ground. He felt the symbolism of the feather was fairly clear, that it represented a beautiful part of the bird that remained long after the bird was gone.

As Mike's physical illness progressed, he became physically less able to express himself either by gesture or by voice. After his temperature spiked to 107 degrees, Mike became aware of the gravity of his illness. He still did not discuss his impending death directly, but approached it clearly enough in other ways. For example, he told his psychiatrist, "I must ride this out. I feel like a cowboy." His psychiatrist tried his own association. "A lonesome cowboy?" Mike replied, "I guess so. That depends on what will happen."

FAMILY RELATIONSHIPS

On the day following the first conjoint session, Mike's father visited him. Coincidentally, he ran into Dr. A., who was reviewing Mike's medical progress. Doctor A. told Mike's father that he planned to start Mike on a new treatment and that the new treatment itself was potentially hazardous. Mike's father misinterpreted what Dr. A. had said and concluded that there was a 50-50 chance or less that Mike would survive the next treatment. With this he immediately called Mike's brothers and other relatives.

When Mike and Kathy found out the message that had been delivered to the family members, they were each very angry in their own ways; Mike because he did not like to be surrounded by "long faces," and Kathy because she felt that the doctors had been keeping information from her. She was quite upset by both the news and the way she heard of it. She called Dr. A. and, by being assertive, managed to get through to him. She found out that the treatment was not nearly as dangerous as Mike's father had presumed. However, Mike's family was already coming from distant parts of the country. Kathy strongly impressed upon the hematologist that she wanted to be present at any future discussion of Mike's condition or prognosis. Coincidentally, in all the confusion, Mike developed a fever and had to be transferred back to the medical unit.

During the next individual session with Kathy, she related with some pride that she had been able to be more assertive with Dr. A. and to see to it that she got what she needed from him. Kathy also was able to be more assertive in the following week with Mike's relatives. His parents kept insisting that a minister

visit him in the hospital. Mike resented this because he and Kathy were agnostics. But his parents would not relent until Kathy firmly confronted them about this.

Mike's brothers insisted on taking pictures of him in the hospital, and the whole family gathered around as if he were going to die within the next couple of days. Mike was upset at the pessimism of his family members. He was very intolerant of anyone who indicated that they might feel bad about his disease. He persistently dissociated his feelings from his impending death. As a result, he refused to enter into conversations with his brothers except under his rules. Because his rules included no expressions of sadness or of loss, the conversations between him and them were characterized by a strange sense of unreality; of a stilted, polite, and largely irrelevant aura of suspended feelings. During brief periods of conversation with Mike's psychiatrist, Mike's brothers expressed bewilderment and estrangement.

RELATIONS WITH THE HOSPITAL STAFF

Kathy became increasingly frustrated that she was unable to get any kind of clear communication from the doctors on Mike's condition or prognosis. This mounting frustration may have added to her anger at Mike's family. Finally, she asked the family to leave, for with their visits Mike's condition seemed to deteriorate. He developed pulmonary emboli and had to be put in intensive care (ICU). Kathy was frightened by this.

Communication with the doctors did improve while Mike was in the ICU. His intern began to meet daily with Kathy to keep her filled in on what was happening. This extra effort on the part of the intern was quite helpful to Kathy. Ironically, just a few days earlier she had scapegoated the intern for many of the problems in Mike's management. The intern had wanted to allow Mike to go home on a weekend pass. He arranged a pass and announced it to everyone. But then Dr. A. vetoed it because he wanted to try a new experimental treatment and because Kathy and Bob had developed colds. The intern was quite upset because he only wanted to allow Mike some time out of the hospital. He was worried that Mike would never leave the hospital alive. Nevertheless, Kathy's reaction was anger at the intern for "acting like he was in charge when he wasn't," and "building Mike's hopes up to go home when really he had no right or authority to do that." She felt that the intern was being inconsiderate. Yet, later when Mike's condition deteriorated and he lapsed into a semi coma, the intern's daily conferences with her became invaluable.

After Mike lapsed into a semi-comatose state, Kathy found it quite difficult to cope with the "chronic crisis." He was in this state for nearly a month. Almost every day the doctors would predict "He probably won't be here tomorrow." Kathy became much more assertive and vocal while Mike was in his moribund state. She strongly defended his rights to get medical care and humane sensitive treatment. When nurses would break the protective isolation rules, she would

strongly confront them about this. She also was able to confront the doctors when she felt that their behavior was remiss. It was noteworthy that while she increased her ability to be frank and honest in situations that involved Mike's critical care, her assertiveness did not generalize to other situations. For example, her real father finally visited Mike. When he did, he smelled heavily of alcohol, and it was apparent that he was not of much support to Kathy. However, when asked about her father's visit later, she mentioned that her father had not had a drop of alcohol for years. In contradistinction to what she had said before, she then claimed that her father had been quite reliable and available to her when she was a child and that it was a problem only when she was a teenager.

There were other problems with her assertiveness and frankness. She could stand up quite well to the nurses but less well with the doctors, especially Dr. A. He would come into the room with a group of medical students, completely ignore her, and talk about Mike's serious condition at the bedside. This made her angry, but she was only able to say to him, "Don't you think you ought to talk about that outside? He can hear you, you know." Dr. A. just ignored her after replying, "No, he can't hear, he's in a coma." Kathy let it go at that, although she knew better; just minutes before she had been communicating with Mike. Although Mike could not talk, usually remaining with his eyes closed, he could respond effectively by nodding his head. It seems that she was able to express her anger so well at the nurses that she displaced much of her anger onto them. They were scapegoated for the anger she felt toward the doctors, and possibly toward Mike for abandoning her. Generalizing, she became increasingly concerned about the care available to dying patients. She expressed a desire to do something about this in the future.

During this prolonged crisis of Mike's semi coma, Kathy asked the psychiatrist to be more of a friend. She said this was what she presently needed, and she expressed some anger at his "psychiatric" attitude. He complied with her wishes for the most part but also told her that he would reserve the right to assume a psychiatric role at times when it would be helpful. As a symbolic gesture, he discontinued seeing her in his office and began visiting her on the medical wards of the hospital where Mike was a patient.

Kathy found it very difficult to handle the state of chronic crisis. She could not remain hypervigilant as she felt she should, and she felt some guilt as a result. She sometimes hoped that Mike would just hurry up and die so that it would all be over. Her ambivalence and anger were exemplified by contradictory attitudes: on the one hand she was furious with the nurses for not strictly observing isolation protocol to protect Mike from infection; on the other hand, she was angry at the doctors for giving Mike antibiotics and blood transfusions that she felt were heroic. Less than two days before Mike's death, Dr. A. wanted to try Mike on a course of nitrogen mustard. Kathy was very uncertain about whether to go along with this. She discussed it in detail with Dr. A. and then in detail with the house staff. It was obvious that the house staff no longer felt that any treatment was

really indicated but encouraged Kathy to go along with the treatment anyway, without being fully aware of, or explicit about, their motives. They felt that nitrogen mustard would only serve to speed Mike's death. Her psychiatrist, who was present, insisted that they communicate their motives more explicitly. They realized then that if their goal was to speed Mike's death, it would be more direct and honest to discontinue the antibiotics and blood transfusions rather than to use the nitrogen mustard for this purpose. It was hoped that this clarification would help to prevent Kathy from unwittingly accepting responsibility for terminating Mike's life, which could result in her feeling guilty later.

The intern and resident, in what seemed a spirit of generosity, quickly responded by telling Kathy that they would go along with whatever decision she wanted to make. If she wanted the antibiotics and blood transfusions discontinued, they would respect that. After they left, Kathy was asked how she felt about that; whether she felt that the burden of deciding when Mike would die was being put on her shoulders. She realized that the decision was being given to her, and she resented it. However, she bravely assumed it anyway, but did decide to dissipate some of the responsibility around the family. She called Mike's father and presented the situation to him. Mike's father discussed it with the relatives and then phoned Kathy and said that he agreed that the nitrogen mustard should not be given and that antibiotics and blood transfusions should be discontinued.

After he heard that Kathy had vetoed the nitrogen mustard infusion, Dr. A. made a special visit to the hospital to see her. This was the only time he had sought her out, and on this occasion he saw her only to try to convince her to change her mind. He tried to persuade her by trying to make her feel guilty about killing Mike. However, she was able to stand up to him and did not weaken under the pressure he was applying. But she did not directly express any anger at him for what he was trying to do. Then Dr. A., in a punitive effort, told the house staff to force Kathy to sign a release of responsibility for the hospital because she refused the nitrogen mustard treatment. However, the house staff just ignored him and supported Kathy. Earlier the attending staff of the hospital officially stated that Dr. A. had no authority to make decisions for Mike's care, and that he could function as a consultant only. The house staff not only supported Kathy in her conflict with Dr. A. but, after a brief psychiatric consolation, reassumed some of the responsibility for the discontinuation of the antibiotics and blood transfusions. Two days later after it was decided not to use nitrogen mustard, Mike died. Kathy gave her signed consent for a full autopsy, but none was performed.

On the day following Mike's death, Kathy's demeanor was again that of a "brave little soldier," whose voice trembled on the verge of tears, but only a few tears fell.

About two weeks after Mike's death, we received a letter from Kathy. She seemed to have found a balance between her need to mourn her loss and her need to reinvest her interests in the present and future. She still strongly felt that Mike's

and her emotional needs were neglected by the nursing and medical staff. She still felt a strong commitment to see that this could be changed for future patients. She had not been able clearly to communicate to her son Bob the meaning of his father's death, as he was not yet three years old, but he had been able to attach himself to some other males who were available to him, especially Kathy's stepfather and uncle.

ISSUES AND QUESTIONS RAISED

This whole experience presents critical issues in the management of the dying patient and the family. The first issue is the interpretation and treatment of Mike's mania. Could not such a state of massive denial and extreme energy be adaptive to a dying patient? We thought about this and decided that it was not adaptive because Mike did not live in a vacuum. But don't we all need to deny to some extent? How much denial of our mortality is healthy? We certainly would not have wanted to take all of Mike's denial away from him. Yet continuous rumination over his mortality and his manic attempt to live all of his life at once interfered with the opportunity to relate actually to those he loved and cared for.

A second issue was the need for a more definitive death trajectory. The critical importance of a clear death trajectory is sadly illustrated in Kathy's agonizing decision over whether or not to abort. From what she said, if she had known he was going to die so soon, she might not have aborted.

A third issue is what role a psychiatrist should play with a dying patient. With both Mike and Kathy, each of us was called upon to be a friend. On the other hand, being a friend was not sufficient to resolve the conflicts of human relations of this young couple.

A fourth issue is who should be responsible for deciding how long the patient's life should be prolonged, or how vigorously the patient should be treated when the situation is hopeless and the patient cannot make that decision. Who makes the decision? Doctors? The family? Or does one choose, as we did in this situation, that it should be a mutually shared decision? If so, how does one split and share the responsibility? Or can it really be done at all? Should the physician take responsibility for decisions to obviate any long-term guilt in the surviving relatives? In this case, the physicians alternately took all the responsibility and then took none. We suggest a third alternative of shared responsibility between physicians, patient, and family.

A fifth issue was the handling of displaced anger. A simple hypothesis is to conclude that Kathy's displaced anger onto the nurses and others was a result of her repressed anger at Mike for dying on her and abandoning her. After all, she never did express anger at his dying, which is so frequently a part of the bereaved's reaction. But need everyone experience that? Maybe anger at the loved one who is dying is really a displacement of an internal anger. After all, what is

the anger about at its core? Maybe it is anger at the frustrating existential realities of loss and mortality.

A sixth issue is the whole scapegoating problem within the social system communication network. The social network of Mike, his family, Kathy, the doctors, the psychiatric staff, the nursing staff, and Mike's friends are a rather loosely connected network. Not everybody within that network talks to one another. In other words, as a social network, they do not comprise a social group. When all those involved are not speaking with all the others involved, the situation is ripe for faulty communications, especially when many people are purposely avoiding communication out of fear, anger, sadness, or whatever. One of the things that happened early in the case was that the doctors would talk to Mike and Kathy separately. They would give one story to Mike, which was sugarcoated, and they would give another story to Kathy, which was more factual. Then when Mike and Kathy would try to discuss things together, it frequently led to discord. Kathy would feel that Mike was denying and not wanting to face up to things. Mike, on the other hand, felt that Kathy was being unnecessarily pessimistic and was just trying to bring him down. They would at times end such discussions by accusing the other of lying.

A communications paradigm helps to explain why certain people were scapegoated. It seems that anyone in this kind of loose social network who is not communicating clearly with those around him or her is leaving himself or herself open to be scapegoated. This happened repeatedly. The orderly on the psychiatric service, who became the single focus of Mike's anger, had not bothered to explain the legitimate reason why he had awakened Mike at five in the morning. When the intern did not discuss his motive with Mike and Kathy, he received Kathy's anger for trying to send Mike home on a weekend pass. She did not know that what he was doing was really a very generous and sensitive act. All that Kathy knew was that he had played a part in events that ultimately turned out badly. Not knowing what his motivations were, she could easily scapegoat him. just before Mike's death, the nursing supervisor of the hospital happened to be making rounds, randomly asking patients and visitors what they thought of the nursing care. When she asked Kathy what she thought, Kathy proceeded to pour out her anger and frustration about what she felt was a lack of sensitivity on the part of the nursing staff. The nursing staff was quite shocked and hurt by this negative. feedback, for most of them felt very sad about Mike's tragedy. However, they were at a loss for words and had not communicated this to Kathy. Upon being scapegoated by Kathy, the nurses reacted by scapegoating the psychiatrist, who had left himself open for this by not communicating with the nurses over the last couple of weeks. They decided among themselves that the psychiatrist must have planned this and had put Kathy up to it, and that he had done it to treat her depression. This was quickly discussed with the nurses and the lines of communication were cleared, at which time the nurses requested that the psychiatric consultant conduct a conference on the management of the dying patient in the near future, which he did.

It is also not unlikely that the hematologist, Dr. A. was one of the ultimate scapegoats of the social network. It is difficult to know what amount of his perceived insensitivity was truly valid. Among all concerned, his communication was certainly the most deficient. Because of his lack of communication, it is quite possible that the social network was inaccurately assessing his motivations without the opportunity to correct misconceptions through his clarification. It is also possible that the house staff allowed him to take much more responsibility for a much longer period of time than was appropriate because it was easier emotionally to have him take responsibility and then criticize him for it—to pass the buck" to him and then scapegoat him.

With such a loosely-constructed social network involved with this dying patient, it seems unavoidable that there would be some scapegoating. Although it is unavoidable, it also seems likely that the displacement in scapegoating could be markedly diminished by training of hospital staff, by regular conferences that include all members of the social network, and by maintaining collaboration between the patient, the family, and the staff.

In conclusion, there were a number of stressful issues confronting this young couple. Our experience here shows that both Mike and Kathy had the ability to cope with these stresses. However, the ambiguity, double binds, coercion, and even simple lack of information that characterized this social system created an intolerable stress. Thus, the social system changed the stress of dying into a crisis of dying. This young couple could cope with the dying process, but they could not cope with the dysfunctional social system. These observed in the hospital may not reflect the problem of dying but rather the problem of the social system.
