

Care of the Patient with Hematologic Malignancy: A Point of View

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The patient with hematologic malignancy is nowadays afforded longer periods of remission through appropriate chemotherapy and, while this provides comfort and encouragement to the patient, the usual outcome is death. The problems that face the patient, the families of patients, and the primary care physician during the course of malignant disease are discussed.

Perspectives on the reactions of all concerned are presented for three phases of illness: The Initial or Diagnostic and Remission-Induction Phase, The Treatment Phase with its remissions and exacerbations, and The Final Phase, or dying process. Case presentations are used to illustrate the problems which affect patients, their families, and the physician. While pharmacologic treatment is important and essential, emphasis is placed on emotional support to be offered by the physician and his team throughout the three phases of illness.

Patients with hematologic malignancy live longer now as therapy for these diseases improves and, unlike in many other fatal illnesses, these patients are often clinically well during much of their illness. The topic of the dying patient is currently receiving much attention, but much less emphasis is being given to the problems of patients living with their fatal or potentially fatal disease.^{1,2} While the current status of hematologic technology has made possible significant advances in the outlook for these patients, some aspects of treatment (eg, laminar flow rooms or cooperative chemotherapy studies) tend to de-emphasize the patient as a person. We believe there are consistent patterns in

the reactions of patients to the diagnosis of hematologic malignancy, and that these reactions can be modified in a positive way by the physician. We submit that it is even more important to help a patient live happily than it is to help him live long.

Repeated interviews with a series of 16 patients with hematologic malignancies (13 with leukemia and three with lymphoma) were the stimulus for this paper. All patients were hospitalized at the time of the interviews, and all subsequently underwent treatment for their disease with currently popular chemotherapeutic regimens. Six of the patients were children (ages four to 14), and in their case the main focus of the interview was with the parent or parents, since many times children are unable to comprehend the seriousness of the situation and do not have a realistic concept of death.

The course of a patient with a hematologic malignancy can be described as consisting of three parts. The first, or initial phase, consists of the

patient's first response to hearing the diagnosis and his early attempts to adjust his life. This coincides with the physician's effort to induce a remission in the illness. The second, or active treatment phase, includes the patient's attempt at "life as usual" (he usually feels well) and the physician's attempt at maximally prolonging the remission. The final phase comes after medicines fail, and consists of the dying process. Burgert has likened these three phases to a hurricane, with the initial storm (phase one), the eye (phase two), and the reverse wind (phase three).³ The following discussion of the care of these patients will be divided in accordance with the three phases of the illness.

Initial Phase

Illustrative Case — V. R., a 33-year-old white female, was motivated to visit her family physician by symptoms of increasing fatigue and bruising. A blood count revealed immature cells in the peripheral blood, and the patient was referred to a hematologist who made the diagnosis of acute myeloblastic leukemia. Upon being informed of her diagnosis, the patient's initial response was one of shock, disbelief, and depression. She later described herself as being literally "stunned" upon hearing the diagnosis and said that it "really knocks the props out from under a person." The patient had a relatively active religious life and soon began to express anger at the fact that she, with her four children, had such a disease. This anger was mainly directed at God. After considerable counseling with both her physicians and her minister, she developed a realistic and functional denial system that allowed her to return to

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her family and function effectively after she achieved a complete remission.

The relationship between the physician and the patient with leukemia depends upon several factors. At the outset, when the disease is first recognized and the patient is made aware of the diagnosis, the most likely result will be shock and anger on the patient's or family's part. This anger may well be directed at the person responsible for making the diagnosis and informing the patient or family.⁴ The physician's ability to accept and deal with this anger is crucial, since his failure to do so may well mean the end of the relationship. He must recognize anger as a defense mechanism of displacement against the unacceptable realization that death is inevitable. Anger can also be directed at other areas: anger at God (the "God, why me?" attitude) or anger at self or loved ones. Thus, the physician's first responsibility is to recognize this fact and not view the patient's anger as a personal attack which may lead him to reject the patient totally. It is important to allow the patient and/or family to ventilate this emotion and help them understand why this is happening. Although superficially the anger may appear goal-directed, it usually constitutes an earnest cry for help, as well as a defense against anxiety.

Another problem that frequently faces the physician in the initial stages is the patient's tendency to doubt the diagnosis and want "another opinion." This, at first, appears threatening to the physician and he may respond in a negative way, perceiving this behavior as distrustful or even as a questioning of his competence. Here, again, it is of paramount importance that the physician be able to accept this on its true merits: most of us would feel the need to verify such a horrendous illness. Often we do so in the hope that a mistake has been made or that someone else might make the disease go away. This, too, constitutes a defense against the anxiety of accepting finality, and it should certainly be complied with.

Active Treatment Phase

Illustrative Case — A. F., a 28-year-old business executive, came to his physician with a symptom of increasing fatigue. A blood count re-

vealed anemia, thrombocytopenia, and immature leukocytes in the peripheral blood smear. This prompted referral to a hematologist who made the diagnosis of acute lymphoblastic leukemia. The patient was an extremely aggressive, rapidly rising young executive in his business and, at his own admission, "put his job before everything." His initial response to the diagnosis was a feeling that his life was ended, and he would no longer be successful in his major goal of rising to a powerful position in his company. After considerable thought and counseling with his physician, and after obtaining a complete remission, this patient made a remarkable shift in his priorities. For the first time, he began to appreciate his family and to realize that "the world is beautiful." His newfound enthusiasm for life was contagious, and his subsequent visits to the hematologist's office improved the days of those working there. This patient truly mastered the much recommended philosophy of "living one day at a time."

Once the patient and/or family have accepted the reality of the situation, it then becomes the responsibility of the physician to provide treatment and support. The treatment itself is primarily in the chemical area and should be designed to augment remission as well as provide whatever comfort is available from secondary symptoms. The support, which is equally important, should be directed towards the emotional conflicts that are certain to be an integral part of the patient's problems. This support is often the most difficult part of the overall program, since most physicians are extremely uncomfortable in dealing with the dying process. Multiple factors lie behind this physician attitude, but the most likely explanation is the physician's own discomfort with death and dying. It is difficult to overcome negative feelings about one's own prospects of dying or related experiences of death or potential death of loved ones.

It is important again to be able to recognize the various defense mechanisms that are utilized by patients or families who are in the process of working through their anxiety and grief. Kübler-Ross has identified five basic defenses that people tend to employ when faced with their own death or the death of a close relative.¹ These are denial, anger, bargaining,

depression, and acceptance; they may occur in sequence or sporadically. We have already discussed the anger and resentment mechanism, and it bears repeating that it is very important for the physician to recognize its true cause and effectively deal with it.

How one deals with denial, which is another common mechanism, depends on several factors. Denial can be healthy and may need to be supported as, for example, in the young child who is unable to comprehend the illness or its consequences. Little could be gained by trying to break through this defense. On the other hand, denial could be pathological and destructive, especially if it led to the patient's refusal of treatment because he "wasn't sick," or in the case of a person who had important matters to attend to. Much of the decision as to when the denial should be fostered or worked through is a question of judgment, and often consultation with family members or friends can be helpful to the physician.

The other defense mechanisms are less likely to be troublesome for either patient or physician and, if they occur, can generally be handled.

Final Phase: The Dying Process

Illustrative Case — J. C., a 26-year-old white female, underwent a spontaneous abortion of a fourth and unwanted pregnancy. Following this, the patient developed excessive hemorrhaging that led to the diagnosis of acute myeloblastic leukemia. This patient became depressed because she felt that "God was punishing her for wanting to get rid of the baby." After a long and arduous remission induction attempt, the patient developed *Pseudomonas sepsis* while continuing to have predominantly leukemic cells in her bone marrow. At this point death seemed imminent and, after discussions with both the patient and her husband, it was elected to emphasize morphine and emotional support rather than additional chemotherapy, hopefully making the patient's exit from this world as painless and dignified as possible. She died holding her husband's hand.

While this is not a typical case to illustrate the dying process, it does serve to point out the need for the physician to be most supportive when the disease appears to be approaching the end. In this case, the physician was

faced with the responsibility of helping the patient and her husband make the choice between prolonging agony and a dignified death. The judicious use of analgesia is one form of support urgently needed, but hopefully the physician can also provide emotional support for both patient and spouse.

No matter how encouraging the remissions produced by chemotherapy, almost all adults and many children with hematologic malignancy reach the final stage of illness, the dying process. It is then that all the skills of the physician are called into play, for this is the most difficult time for all involved.

The treatment of a patient who is dying varies from institution to institution, but it is not uncommon to see the care personnel begin to withdraw physically and emotionally from the patient. Hospitalized patients who are dying are frequently moved to private rooms, where the door is kept closed, and contact with anyone other than close family is at a minimum. The physicians tend to shorten their calls on rounds, and the nurses do their work quietly and efficiently, but spend very little time in accomplishing their tasks. Perhaps the only hospital personnel in longer contact with the patient is the cleaning lady, who must spend a certain amount of time to do

her work in the patient's room.⁵

What a paradox this is! At a time when the patient needs us most, we tend to withdraw. At this stage of the illness, the quality of the relationship established in the initial phase and hopefully continued through the active treatment phase will govern the amount of positive support the physician can offer the dying patient and his family. The job of keeping the patient physically comfortable is important, but relatively easy compared to providing emotional security and comfort. As the leader of the treatment team the responsibility for this does rest with the physician, although he may want to enlist the aid of other support resources, such as clergy, paraprofessionals, or friends. How easy it is to be skilled as a physician and scientist and how difficult it can be to be skilled as a human being!

The process of dying is little understood by any who have not experienced it, and those who experience it are rarely given the opportunity to communicate. It would be well for all who will be responsible for the care of the dying to introject the following thoughts for a better understanding of what dying is all about:⁶

You look at me.
You wonder if I am afraid to die

Because you are afraid.
You do not know that death
might be relief,
Might be the refuge that I seek,
The rest I need so desperately.
You are afraid because you are
too far away
To sense the comfort, peace, and
sweet release of death.

I do not choose to die,
But greater dread to live too long
Beyond control of my own destiny.
I tremble — wait a moment on the brink
To test my faith
Ere plunging, with no hope of turning back,
Into timeless immortality.
You look at me.
You wonder if I am afraid to die
And so do I.
I only know I fear not death
If I survive the dying.

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