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10 Thomas L. Lincoln, M.D.

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CANCER DECISIONS - WHAT PATIENT? WHAT THERAPY?*

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CANCER DECISIONS - WHAT PATIENT? WHAT THERAPY?

When faced with the diagnosis of cancer, what should a patient do? Should he be treated in his local community? Should he go to a major center? Should he go to a university hospital? Are these the alternatives? Why is it that the more physicians and laymen one asks, the more opinions one gets? These are questions which I try to answer two to three times a week as a volunteer consultant to the Leukemia Society of America. It usually takes more than an hour.

About one-half the time is spent discussing the particular illness of the particular individual; however, there is a central theme to every conversation which touches on a critical issue of biomedical communication: the communication between the scientifically and technologically qualified personnel of the health care system and the individual layman. To jump ahead to the conclusion, it appears that we need an ombudsman, as in many other areas of modern society. A great deal has been made of the user of health services as a consumer. When faced with serious illness most of us are reluctant consumers. If possible, one would prefer to be an investor. Whatever we do will cost money, time, effort, and personal discomfort. We do not wish to consume medical services. We want to invest in them, and we hope for some return on our investment. By design or default, the cancer patient is an investor who may seek to minimize his immediate losses in terms of discomfort, illness, or shortened life span - or he may seek to maximize his long term gains and accept a higher intermediate risk. We need an investment counselor who can assist the individual in deciding how he should invest his energy and his life given a serious medical threat. The choice among these alternatives should be based on the risk preferences of the patient, not those of a particular physician. This is not, however, generally the case.

The layman comes to the diagnosis of cancer with some general impressions, commonly a mixture of experience, folklore, and certain highlights treated in the press. He relies heavily on his physician for advice. A paralysis of personal judgment is not uncommon. In my advisory position to the Leukemia Society of America I hear from that group of people who

respond to crises by seeking information. They are dissatisfied by advice dogmatically given and look for some perspective on their dilemma. Many are merely acting prudently. One group of the individuals that I advise are managerial or professional and by nature are reluctant to accept unverified advice. Others feel that they have been denied such perspective by their physicians or by the health care system. For example, they are commonly denied the use of hospital library services. Some call early after a diagnosis and appreciate that decisions once taken are not lightly changed. Another group calls late in the disease course when most fruitful options have disappeared.

For those who call early I outline the alternative approaches which responsible medicine takes and give these alternatives some thematic meaning in terms of investment opportunities. I also try to shed some light on arguments about therapy which I consider to be minor differences of opinion. In short, I try to describe how our pluralistic medical system works in this area, and how its specialized jargon can be interpreted.

Despite all that has been said and written about cancer, cancer research, and medical advances, it is surprising how few people are aware of the orderly process of research and development which generates present and future therapies. Patients are generally unaware that they can choose to participate or not to participate in such a program. This research and development process generates the alternatives and gives each their particular character.

I describe the treatment alternatives as follows: one part of the health care system follows the established odds as the most reliable means of treating a particular cancer. The objective is to minimize complications and to match risk to generally available facilities. The horizon for the future is generally short-term and the approach is similar to coastwise navigation; minimize the difficulty of arriving at the next checkpoint and the long-term results will take care of themselves. This is the approach usually found in private practice, in institutional practice such as the military, and in prepaid health care group practice. The choice follows the rule that what is familiar is the safest. The choice is neither right nor wrong, it merely minimizes short-term risk and as far as possible early catastrophic loss. It generally minimizes

cost. High cost complications are deferred as are often high cost services. If deferred long enough, the patient's instability can be so great that such services are only needed for a very short time. By the same token, in the short run, a nearly uninterrupted life may be possible.

The greatest contrast to this approach is represented by those major cancer centers in the country which have as their objective, beating the present odds. These programs are properly called developmental and not experimental - if only because in layman eyes to be "experimented upon" in either some form of wild-cattling or something akin to a horror movie. Experiments are done in the laboratory prior to therapeutic development in man. The sequence of events which lead to a new therapeutic approach must be pointed out to demonstrate the discipline and control involved in beating the odds. To organize a program to beat the odds is no more accidental or arbitrary than organizing to win the Indianapolis 500. To beat the odds is to have a longer productive life. However, like the Indianapolis 500, the risk that something may go wrong is greater. To beat the odds is to achieve a closer match between diagnosis and therapy. To beat the odds is to be prepared for success. To beat the odds requires a focused, single minded team, logistic support, and patient physician collaboration. To be first is to be a test pilot. It is not for everybody. Here the costs are greatest, but the overall program is most heavily subsidized, and over the long run some of those who have participated in such programs have achieved the most striking results.

There is an intermediate choice - the highly formalized clinical trial carried out by universities and collaborating institutions. There is an important distinction here which must be emphasized. The prototyping institutions and programs also run clinical trials, but here, although the vocabulary is the same, the objective and philosophy is different. The objective of most clinical trials is dependent upon the clinical environment. Thus, the intermediate choices are those programs which are evaluating the best of the prototypes - How successful is a therapeutic program when carried out by well informed staffs in well equipped hospitals? Is the promise of improvement sustained? Here the

emphasis is on orderliness and evaluation, and there is greater rigidity than in either of the other choices. In general, this choice tends to introduce more technology earlier and introduces more active intervention using chemotherapy and other modalities than in private practice. Certainly adjuvant early chemotherapy for breast cancer is an example. But there are notable exceptions. In smoldering leukemias, in certain non-Hodgkin's lymphomas, and in hairy cell leukemias, the more advanced therapy tends to minimize active treatment.

These sketches do not do justice to the major themes of cancer treatment, but they do provide perspective. I have not discussed marginal medical judgment and practice nor the ever-present something-for-nothing proposals of the cancer fadists. These latter feed upon various kinds of communication failure and communication pathology in the responsible community. Like disease itself, they will surely not go away. Their choice is a failure of medical guidance and trust.

It is my view that the patient and the patient's family should have the opportunity to choose the kinds of therapy they want according to their own risk preferences. It is my view that federal programs, private insurance and practicing physicians should not trap individuals into choosing one kind of program or another either by manipulating incentives or by manipulating information. The health care system should provide the time, the information, the compassion, and the necessary professional modes of referral to match patients to their legitimate expectations.

I touch upon this problem today not because I have an easy answer, but rather because it puts the focus of our discussion beyond technology and beyond the tactics of the present. As we discuss communication and bioscience, we will be forced to deal concretely with narrower issues.

As we talk about technology and about decisionmaking, and about communication, it will serve us well to think about technologically assisted decisions and to consider communication aids to the process of decisionmaking in such a way that the means does not escape the purpose.

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