MATTERS OF LIFE & DEATH: RISKS VS. BENEFITS OF MEDICAL CARE

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PREFACE

The past 20 years have seen an unprecedented accumulation of medical knowledge. This has been accompanied by a growing and unprecedented disillusionment with the application of this knowledge to patient care. Dissatisfaction is expressed by increasing numbers of patients and is even shared by many doctors. In fact, when the doctor becomes a patient, his anxieties may be even more intense than those of a medically untrained person. At the very time that medicine has achieved a new pinnacle of formal progress, confidence in its relevance to patient welfare may be approaching a nadir.

This paradox has not gone unnoticed. Numerous publications deal with one or another of the perceived causes—economic, political, cultural, scientific, or societal. Most analyses have not directly challenged the system whereby medical knowledge is applied to patient care. This book, written primarily for the general public, makes such a challenge. It stems from my conviction that there are major but reversible flaws in the present system of medicine; that these flaws can be understood by most patients and potential patients; and that while waiting for medicine and society to correct these flaws, patients themselves can help minimize the risks of modern medicine.

I do not regard this book as heretical or myself as a heretic. I do believe in some things. I believe that the purpose of medicine is to help patients directly. I believe that we need more, not less, science in medicine, but it

has to be better science and more closely linked to patient welfare than it is today. I believe that medicine can be markedly improved but that this improvement will not happen automatically. I do not regard myself as an iconoclast even if I succeed in smashing a few idols. Nor do I consider myself a medical nihilist. I have tried to provide constructive alternatives to those features of medical care I consider wrong or inadequate.

Nor am I a professional critic of medicine. Actually, I am a teacher and researcher. In my research, I am trying to unravel the mechanisms by which lack of oxygen affects genetic expression of cells—hardly a controversial area. I teach physiology and clinical management to undergraduate medical students, interns, residents, fellows, and physicians in practice. I tell them much of what I will tell you, with varying degrees of success. I am also a doctor, involved in the care of patients. I like to think that I do that better than I used to because I am more critical of myself and my colleagues than I used to be. I certainly feel more humble than I once did.

This book grew out of a series of teaching exercises for doctors that I have conducted during the past five years. Underlying those exercises and this book are certain assumptions:

- The goal of doctors should be to help patients as much as possible (hardly a revolutionary or world-shattering assumption).
- Much of what we doctors do is tangential to that purpose.
- Much of what we do is harmful.
- Many of the tangential and harmful aspects of medical care could be changed.
- We doctors should take the major responsibility for changing them.

Although there have been notable exceptions, on the whole the reception of these teaching exercises by other doctors has been surprisingly favorable. This encouraged me to believe that the material might be useful to non-doctors also. This book, then, is for everyone who is or might be a patient.

Many of the ideas I present in this book are not original with me, but I accept the responsibility and blame for whatever is wrong or harmful. Whatever else you may get from the book, I hope it will encourage you to evaluate more critically the opinions furnished by medical experts—my own included.

Many of the concepts developed in this book have not been subjected to experimental verification. For many of them it would not be possible to do so. You may consider this an important weakness in my argument. You will have to trust or reject my ideas on grounds of logic, intuition, or personal experience.

I have tried to be precise about facts, primarily because it is the right thing to do, but also because the book may be subjected to unusually close scrutiny. If any inaccuracies have escaped me, I apologize, but I hope that

you will not be distracted by these from the main thrust of the book.

I have provided a glossary of terms, many of which you may already know. In my choice of what to include I have supposed that everyone knows a congenital disease is a disease one is born with. Not everyone may know, however, that congenital diseases are not always inherited (i.e., genetic in origin), but may be acquired in the womb; for example, as a result of a uterine infection or a drug given to the mother. Most everyone, I imagine, knows that a cardiologist is a heart specialist.

I have not provided a reading list because, in my opinion, the medical literature is imperfect and contradictory. Using it selectively to support my views would provide unjustified support and a sense of false erudition. This book deals with very fundamental attributes of medicine, and fundamentals are usually impossible to prove. In the last analysis, this book represents my own opinion, as it must.

I feel uncomfortable using "he" and "his" to include both women and men, but I could not find a solution that did not seem artificial and distracting. I hope that linguists will soon come up with a term that embraces both genders.

Though not specifically written as a textbook, this book can be used as a nontextbook textbook. You can even, if you choose, participate in a formal examination that will test what you may have learned while "studying" the text (see back of book for details). On the other hand, you may choose to read it casually in whole or in part. Whichever alternative you choose, I hope that you learn as much from the reading as I have learned from the writing.

Eugene D. Robin

Stanford University
September 1984

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I also acknowledge as an important source of reference, *Medicine Out of Control, The Anatomy of a Malignant Technology* (Sun Books, Melbourne, Australia, 1979) by Richard Taylor. I disagree with many of Dr. Taylor's conclusions, but I agree with some of his material and the book has been generally helpful; in particular, a title used in his book inspired the title of Chapter 12 in my book.

Laura Ackerman-Shaw, production manager of the Portable Stanford, patiently and expertly turned the manuscript into a book. Miriam Miller, the editor of the Portable Stanford, made numerous contributions to the writing of this book. The original suggestion that the material might be of interest to the public was hers; she edited and polished the text; and, most important, she protected me—as much as one can be protected—from the inadequacies of my own writing style. I am more than grateful for her guidance.

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1

WHAT THIS BOOK IS ABOUT

Not long ago I was involved in the care of a previously normal 40-year-old man with a family. When I examined him, he was in a deep coma. He did not respond to painful stimuli, gave no evidence of any intellectual function, and had no control of bladder or bowel. He did not move. His heart and lungs worked, his bladder and bowel functioned automatically, but there was no glimmer of specifically human behavior. He was a 40-year-old "vegetable."

I reconstructed his story from the hospital record: He had been admitted six months earlier because of fever, progressive stupor, and various neurologic abnormalities. At that time he was certainly a sick patient but definitely not a vegetable. It was thought that he might be suffering from herpes encephalitis, an infection of the brain caused by the herpes virus.

For most types of viral encephalitis, there is no specific treatment, and many patients recover spontaneously; however, herpes encephalitis is usually treated with the drug adenine arabinoside (ara-A). Although the evidence supporting its effectiveness is weak, it is the best drug available. It also has serious toxic effects; it produces severe abnormalities of the bone marrow (bone marrow manufactures various kinds of blood cells). But given the terrible prognosis of untreated herpes encephalitis—death, or irreversible brain damage—most doctors would use ara-A in a patient with definite diagnosis of herpes encephalitis.

To help resolve this dilemma—whether to use a toxic drug in the hope of curing a terrible disease—doctors may order a brain biopsy before prescribing ara-A. Opening the skull, they remove a small amount of brain tissue, which is then examined under the microscope for signs of the herpes virus. The idea of removing any portion of the brain is, of course, awesome. In the adult, brain cells once removed are no longer replaced. Brain biopsy may be associated with irreversible and occasionally fatal complications such as bleeding into the brain.

A brain biopsy had been done on my patient. No herpes virus was found, but almost immediately following the biopsy, he sank into the coma in which I found him six months later. His condition was irreversible; he would be a vegetable for the rest of his "life."

Most of the doctors originally involved in his care were convinced that his dramatic downhill course was a result of the brain biopsy—that he had bled into the brain. It was barely possible, however, that the underlying cause was infection by the herpes virus. Brain biopsies have been known to be negative despite the presence of the virus. Therefore, even though the biopsy was negative, he was treated with ara-A. This treatment produced no improvement, and the patient and his family were condemned to a continuing horror.

The complex issues involved in this case will be analyzed more fully in Chapter 4. But the end result is clear: A patient suffered a horrible fate almost certainly as a result of a test. Doctors then ignored the outcome of the test and treated the patient as if the test had never been done. Could this disaster have been avoided? Why was the test done if the results were ultimately ignored? What went wrong?

You will learn as you read on that disasters like this one are not uncommon and that many diagnostic tests are done despite an overwhelming probability that the results will not be helpful to the patient.

No individual doctor could be blamed for the tragic outcome in my patient. Rather, the basic cause lies in a series of flaws in the system by which medical knowledge is introduced and applied to patient care—and in the way doctors are trained. These flaws foster a preoccupation with the process of diagnosis, which in this instance led to grave and irreversible damage to the patient. The outcome could not be considered the result of medical malpractice.

Malpractice consists of a breach of the community's standards of medical practice. It occurs when a physician's activities do not conform to those practiced in the community. But suppose that most of the physicians in the community are wrong about some aspect of medical care. Then this systematic error represents the standard of medical care and to conform to it is not malpractice.

This book deals largely with the nature of the systematic flaws or defects in medical care and training, rather than with the errors of individual doctors. As will become apparent, I believe that many of these flaws can be overcome by modifying the way that medical information is introduced into patient care, by modifying the way that medical information is used, and by modifying the way that doctors are trained.

I also believe that you, as a patient, can shield yourself from the consequences of many of these flaws. You face a dilemma that you may not even recognize: How to reap the benefits of modern medical care without exposing yourself to the risks. You consult doctors because the potential benefits seem obvious to you, but you are probably not aware of most of the potential risks. In fact, many doctors are not aware of them, or may underestimate their magnitude. This book will emphasize the risks chiefly because an understanding of them may help you to make better decisions with regard to your medical care.

The Risks versus the Benefits of Reading This Book

In reading this book you stand to gain some benefits, but you also subject yourself to some risks: Your confidence in doctors could be undermined to the point where you deprive yourself of timely or even necessary medical care. That would be unfortunate. Conventional medical care does offer the best possibility of helping those who are truly sick.

You run the risk of feeling insecure in dealing with doctors. I would suggest that some measure of insecurity may be appropriate. You may learn some things that will prompt you to look back with a critical eye on your previous medical care and second-guess your current doctors—but learning from previous medical experience is useful. You may find yourself less ready to accept medical advice, but some degree of reservation is often warranted.

What are the potential benefits to you? You will gain a more realistic picture of what medicine can and cannot do for patients. This will permit you to deal more effectively with illness and with doctors. You will come to see how the medical system works. This can be intellectually satisfying but, more importantly, it can help you avoid serious errors in your own care.

You will learn, too, that some medical errors stem from the actions of patients themselves. By learning what not to do, you may increase your chances of being helped when you are ill. You will be advised to consult doctors only when you believe that you are truly ill. By restricting your medical encounters to those that are absolutely necessary, you will be avoiding the risks inherent in most diagnostic and therapeutic procedures.

This advice tends to slight an important function that doctors have assumed in our society: Dealing with patients whose main problem is an unhappy life. It is your privilege to consult a doctor for that purpose, but you should know that few doctors have high cure rates for unhappy lives, so that the chances of getting real help are small. Moreover, your visit may start a series of potentially dangerous medical tests and treatments. If, as a result of reading this book, you see that even the decision to consult a doctor is a serious and potentially risky one, that it requires some estimate of potential risks as well as potential benefits, you will have spent your time well.

You will be cautioned to avoid hospitalization unless you are seriously ill and only a hospital has the facilities for your treatment. Many hospitalizations are unnecessary and, as you will see, hospitals can be dangerous places.

Even the annual physical carries some risk, as do other kinds of routine examinations in apparently normal people, and the evidence presented here may lead you to avoid these.

You will be advised to deal with your doctor as a fellow human being and not as a god. Following this advice should improve the results of your medical care.

You will learn something about the specifics of medical knowledge in several areas of disease. This will not enable you to be your own doctor, but you will find this information intrinsically interesting as well as useful.

I believe that, on balance, the benefits of reading this book will outweigh the risks. I believe that an informed patient is an important asset in health care.

This is not an exposé of medicine. Doctor baiting is a popular sport, but not one that I care to indulge in. Most of the problems of medicine do not arise from inadequacies of individual doctors but are rooted in the medical system. To solve these problems we will have to change both medical teaching and medical care.

This volume, though not balanced in detail, is balanced in emphasis. Because the emphasis is necessarily on the potential risks of medical care, more space will be devoted to problems and less to triumphs. However, the triumphs do exist and are acknowledged.

If some of the cases I have cited as examples read like a chamber of horrors, keep in mind that they are chosen to illustrate problems, and are not necessarily typical of medical care in that area. Neither are they totally isolated instances. Each of the fifty-odd lay people and doctors who have seen parts of this book have described comparable disasters attributable to medical care.

I have deliberately refrained from giving medical advice for dealing with specific illnesses. That is not the purpose of the book. Its purpose is to reveal to you the limitations of medicine in the hope that this knowledge will help you deal more effectively with medical problems.

Many popular books tell you how to deal with individual doctors or with particular problems intrinsic to the present system of medicine. Several of these books are useful. They assume, however, that *(a)* the present system of medical care is fundamentally sound, and *(b)* the reader understands the basic workings of that system.

The present volume, by contrast, attempts to analyze the system, taking as its premise that the system rather than individual doctors is primarily responsible for the harm that patients may suffer. It assumes further that an understanding of the system and its problems will be useful to patients. The terms *medicine* and *medical system* describe the sum total of medical knowledge and medical practice generally accepted at a given time.

It has long been recognized that medicine has the potential for doing harm as well as good. What is not commonly recognized, however, is that the potential for both harm and good has increased as medical science and medical technology have progressed. The number of things that doctors can do and actually do has multiplied enormously. This growth has occurred without appropriate corresponding changes in the processes by which medical practices are established and by which doctors are trained.

I have not (with rare exception) identified specific people. This is a book without villains but with many heroes—patients who endure despite the imperfect state of medicine, and the millions of patients who have served as objects of study or experiment, thus making it possible for medicine to be as useful as it is.

Second Opinions

If reading this book troubles you, you may want to discuss it with your doctor. I have presented the material to many doctors. These are some of their reactions.

Enthusiastic support often comes from doctors who have not kept up with medicine. They see in my views a justification for their failure to keep abreast of medicine. This support makes me uneasy. My message is not anti-medical science or anti-technology. On the contrary, I personally believe that we need more, not less, science in medicine. But we need better science and a medical science more closely linked to the needs of patients. What I do criticize is the inadequate basis of medical knowledge and the common failure to recognize this inadequacy.

The very young in medicine, particularly medical students and interns, tend to be supportive. Their views have not yet hardened. Physicians who have recently completed their medical training tend to be quite negative. They read into the criticisms a challenge of the validity of what they "know" to be true. Their perception is accurate. I do challenge the validity of much of the substance of current medical practice.

Some doctors agree with the general thrust of my book but oppose carrying the message outside the family of doctors. They feel that the lay person does not have sufficient medical background or sophistication to handle the material adequately. They fear that an open public airing will lead to harm by discouraging patients from seeking needed medical care or accepting medical advice.

A number of doctors accept the validity of the criticism when leveled at other groups of doctors but reject criticism leveled at their own group. Cardiologists may be quite scornful when a gastroenterologist's mistakes are laid out. They are, however, not amused at a parallel analysis of the handling of a heart patient by one of their number. Surgeons readily accept criticism of internists but less readily accept criticism of surgeons, and so forth. Many doctors will accept the validity of some, but not all, of what is stated here. Some doctors will, of course, be convinced that this book is simply wrong and harmful to boot. I would urge you to use your own judgment.

What I Hope This Book Accomplishes

My discussion rests upon three major premises.

1. The basic processes for introducing and using diagnostic and therapeutic measures in medicine contain serious flaws.
2. Many of the flaws I describe in the body of the book can be corrected.
3. Patients can reduce the risks and increase the benefits of their medical treatment if they are aware of the flaws in our medical care system.

In writing this book I too have taken some risks but hope for some benefits. The major risk is that my criticisms may stand in the way of your getting proper medical care. I am willing to take that risk because I trust your judgment and common sense.

The major benefit to me is a sense of having provided an accurate description of the limitations of medicine in a way that improves your chances of deriving the greatest benefit from your doctor and the medical care system. That is a rich reward indeed, so I have decided to accept the risks.

2

RISK-BENEFIT ANALYSIS FOR PATIENTS

The principle behind risk-benefit analysis is exceedingly simple. Most decisions in life involve estimates of possible risks versus possible benefits. I decide to cross the street: The risk is that I will be hit by a car; the benefit is that I reach the other side. A formal risk-benefit analysis for this decision would, of course, be absurd; we intuitively learn to watch for cars and cross streets without thinking.

We have learned, too, that the relation between risk and benefit is altered by circumstances. Under normal circumstances, I do not try to cross a busy freeway. If, however, I see someone trapped inside a burning car on the other side of the freeway, I decide to cross. A different *benefit* has developed. I will risk being hit by a car because I may be able to save a life. My decision depends on an estimate of probability: How likely I am to be hit by a car versus how likely I am to save a life. Risk-benefit analyses usually include such an estimate of probability.

What I want to suggest here is that we need to apply the same kind of analysis to medical care, and consciously. Patients should understand that most medical care involves risks as well as benefits. Even the simple act of consulting a doctor has elements of both. When they are ill, patients tend to focus on the benefits of medical care but do not perceive the possible risks. Actually, many of the risks of medical care occur when people are well. In an annual checkup, for example, the risks are not apparent to most physicians, let alone to most patients.

Doctors are routinely called upon to make decisions for which they should perform risk-benefit analysis, but too often they fail to recognize the extent to which, in even simple decisions, both risk and benefit are involved.* Nor do they recognize that their decision cannot be made in an absolute sense but depends on some sort of probability estimate.

Even when a doctor knows the risks of a particular form of management, he may not transmit the information to the patient. Suppose, for example, your doctor tells you, "Do not take this medicine if you have an ulcer, ulcerlike symptoms, bleeding problems, diabetes, gout, or some forms of arthritis. Do not take it if you have asthma or are in the last three months of pregnancy. If you develop heartburn, ringing in the ears, bruises on your skin, a skin rash, wheezing, or sudden death, stop taking the medicine and get in touch with me immediately."

You would probably be alarmed at these instructions, but they are all appropriate for describing the risks of taking aspirin. Your doctor ordinarily does not give you this information. He knows that the probability of your being harmed is small and so he tells you to "cross the street." Unless you were among those few patients who develop one of the complications that aspirin causes, you would be unaware of the potential risks.

For many or most diagnostic and therapeutic procedures, the data needed for a rational decision are simply not available. Much of medical care is based on a limited and often distorted data base and limited experience, so that potential risks tend to be underestimated and potential benefits tend to be overestimated. A method does exist for rationally determining the probabilities of risk versus benefit, and that is a *clinical trial*. You will learn more about clinical trials shortly.

The Cost of Faulty Risk-Benefit Analysis

Let us use a *hypothetical* example to demonstrate what terrible errors can occur in medicine, how many patients may be affected by an error, and how hard it is, because of faulty risk-benefit analysis, to detect systematic errors.

Cancer of the pancreas is a difficult cancer to detect and the prognosis is poor, especially if detection comes late in the course of the disease. Let us suppose that a blood test is introduced which, when positive, is said to indicate the presence of pancreatic cancer; and when negative, to indicate no pancreatic cancer. Ten patients with known pancreatic cancer undergo the test; the test is positive in all ten. Ten controls, apparently normal subjects, believed not to have cancer of the pancreas, also undergo the

*There is a discipline within medical science devoted to developing methods for making risk-benefit analyses that would improve decision making by physicians. This effort is commendable, but often the data base used is so imperfect that the value of the analysis is limited. From the standpoint of patients, it is to be hoped that this discipline will flourish.