Disease, Diagnoses, and Dollars
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Facing the Ever-Expanding Market for Medical Care

Robert M. Kaplan
Preface

Good health is our most precious asset. Without health, life becomes much more challenging. Because health is so central in our lives, we invest trillions of dollars to achieve more wellness or to remedy diseases. A vast healthcare establishment is ready and willing to receive these investments. Some investments in healthcare result in healthier and happier citizens. Other investments have little effect on health, are wasteful, and even harmful.

It is widely acknowledged that there is a serious crisis in American healthcare. There is no real healthcare system in the USA. Instead, we have a patchwork of competing systems. Medicare covers the elderly and people with some defined problems, such as kidney failure. Medicaid covers the blind, the disabled, and families with dependent children. Most people have private insurance that is paid for by their employers. The public systems are in financial trouble, and an increasing number of employers claim that they are no longer able to pay for insurance. The number of uninsured or underinsured people in the USA has soared to well over 45 million.

Proposals for national health insurance abound. However, virtually all of the proposals focus on providing coverage for all people. Although universal healthcare is an attractive goal, there is another problem. We have been persuaded to want more healthcare than we need. A New York Times article by columnist by Gena Kolata [1] described patients lining up for all of the care that Medicare will cover. The article describes patients in a Florida clinic seeking every service that the Medicare program will pay for. They ask for the latest diagnostic tests, and they want the latest medicines that they have learned about by watching advertisements on television. The Medicare system, in some ways, encourages this. If a service is covered, the provider only needs to send in the bill and he will be paid. Is all of this medical care necessary?

This book is about some disquieting conflicts between consumers and their healthcare providers. Our healthcare system is big and complicated: it is the largest sector in the biggest economy in the history of the world. But, unlike other industries, healthcare has not been held accountable for what it produces. We know, for example, that the USA spends significantly more per capita on healthcare than any other country. Yet, we rank last among comparison countries in the Organization for Economic Cooperation and Development
on the major health indicators. We also know that there are substantial regional
differences in healthcare expenditures within the USA. Even when we adjust for
a variety of variables, such as age distribution, poverty, education, or minority
status, regions that spend more do not have better outcomes, and some evidence
suggests that quality of care is lower in the regions that spend more, not less, on
healthcare.

Our problem is not that providers charge too much, it is that they do too
much. We assume that the high costs of healthcare reflect the expense of services
and medications. *Disease, Diagnosis, and Dollars* calls this assumption into
question. Drug prices in the USA are not significantly higher in comparison
with that in other developed countries, because few patients actually pay the
listed retail price. Total costs are a function of two factors: unit price and
volume. Volume, not unit cost, may be driving our healthcare crisis. The
following chapters suggest that mass markets have been created for services
that may offer little or no benefit to patients. Many of these markets are for
preventive medicine. These include cancer-screening tests, and medications to
control blood pressure, cholesterol, and glucose. The attractiveness of preven-
tive medicine is that it can make well people a market for expensive pharma-
ceutical products and tests.

These mass markets have been nurtured with the support of respected panels
of experts who have created guidelines for new tests to diagnose illness and new
drugs to treat disease. New revisions of these guidelines are unlikely to benefit
most consumers of healthcare. Still, these guidelines are used to set standards
for the practice of medicine, and quality of care is often defined as adherence to
the standards. Once the guidelines are set, doctors follow them. We have been
intentionally led to believe tests and medicines will offer greater benefits than
evidence supports. The result: uncontrollable costs and minimal benefits.

There are consequences to the overuse of medications and tests. Although
most screening tests and modern medicines used in prevention are safe for
individuals, their use runs up the costs of healthcare. High costs result in higher
insurance premiums for all of us. As more employers drop health insurance for
their employees when costs accelerate, the expanded use of ineffective preven-
tive medicine may have the unintended consequence of increasing the number
of uninsured patients, potentially damaging the health of others in the
community.

The concluding chapters offer suggestions for policy makers and for
patients. Methods for systematically evaluating the cost-effectiveness of new
guidelines are discussed. The final chapter provides practical suggestions to
enable patients to share in decisions about treatments or tests that can have
uncertain benefits.

Many colleagues have contributed to the development of this manuscript. I
started thinking about these problems 10 years ago during a sabbatical year at
the Dartmouth Medical School. That year I got to know Elliott Fisher, Gil
Welch, Lisa Schwartz, and Jack Wennberg. The Dartmouth experience shaped
my thinking about overuse in medical care. The ideas for the book have been
shaped by a dozen years of experience as a faculty member for the American Health Association US Seminar on the Epidemiology and Prevention of Cardiovascular Disease. The core of the book has been adapted from the lectures I offered at the Lake Tahoe seminar. While a professor at the University of California, San Diego School of Medicine, close colleagues including Rick Kronick, Robert Langer, and Ted Ganiats discussed these ideas with me on many occasions. I am particularly indebted to Mike Criqui, a noted physician epidemiologist who, over the course of 25 years, systematically taught me the basics of epidemiology and helped sharpen my thinking. Mike may not agree with all of the ideas in this book, but I hope he will see that he inspired some of the critical reflection. At UCLA, I benefited from feedback from Gerald Kominski, Tom Rice, Bill Cononar, Dominick Frosch, and several others. Readings of early chapters by Andrea Grefe and Margaret Gaston guided the direction and the prose. I am most sincerely appreciative for the detailed feedback I received from Paul Farrell from Springer and Copernicus Press. Paul critiqued every page, challenged the thinking and the writing, and made the manuscript better in countless ways. My senior editor Bill Tucker has also been exceptionally helpful. Finally, I am most indebted to the Rockefeller Foundation who provided a quiet study in Bellagio overlooking Lake Como Italy, where the manuscript was finally completed. The fellow resident scholars at Bellagio also provided very valuable feedback.

I expect that many intelligent and well-informed readers will disagree with some of the basic premises in these chapters: the book was intended to be provocative. However, the text is built upon data from contemporary, peer-reviewed literatures in medicine and health services research. I hope the book stimulates debate, fosters new research, and makes us wiser consumers of healthcare.

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I can still remember the call. At age 77, Sally, a close friend of the family, had a positive mammogram. I was a professor at the medical school, and her family wanted to know the names of the best breast surgeon and the most distinguished medical oncologist. We all want the best medical interventionists when faced with a potentially fatal illness. After a biopsy, Sally learned that she had a condition called ductal carcinoma in situ, or DCIS. The doctors told Sally that this was a mild form of breast cancer, but the family was unwilling to take chances. She got surgery, chemotherapy, and radiation therapy. Today, Sally is alive and doing well.

After treatment, family members became advocates for early detection in older women. They believed that Sally’s life had been saved because her doctor was “aggressive.” He ordered a mammogram and followed up the positive result with a biopsy, surgery, chemotherapy, and radiation. How can anyone argue with his judgment?

The problem is that Sally suffered considerably. The suffering began with severe anxiety and fear of death. Then surgery, chemotherapy, and radiation therapy took a heavy toll: She lost her hair, lost her energy, and even considered whether death might be a better alternative than continuing medical torture. The aftermath of the treatment included continuing anxiety, concern about memory loss, and depression. New evidence suggests that younger women who receive chemotherapy are much more likely to have serious adverse side effects than was previously recognized. As many as 61 percent of younger privately insured women with breast cancer require hospitalization or visit emergency rooms for serious adverse consequences of their treatment [1]. So, in terms of the pain and suffering caused by the so-called “side effects,” Sally paid dearly for her treatment. And what is more, it is uncertain that the treatment had a significant impact on how long Sally lived. In many countries, screening mammography is not done for women of Sally’s age, and the chances of death from breast cancer in these counties are about the same as they are in the USA [2]. Ductal breast cancer is common in women over 65, and the best evidence suggests that without diagnosis and treatment, the majority of them continue their lives and die of other causes without ever knowing they had cancer [3].
For anyone who has thought seriously about health and healthcare, Sally’s case—statistically “typical,” a perfectly “ordinary” case—the questions raised are anything but ordinary. In addition to the undeniable physical and emotional consequences of her diagnosis and treatment, the interventions were costly, and these costs accrued not only to Sally and her family. Sally was a Medicare patient and paid only a portion of her own medical expenses. However, Medicare costs are out of control, and each time the costs go up there is pressure to cut expenses elsewhere [4], in the hospital, in the healthcare system, and in society at large. Anyone’s individual journey through serious illness and treatment is by its very nature a tremendous personal challenge. But there is another urgent challenge we face together as a society, and how we address it could have huge consequences for the health of the population.

**Buying Health, Buying Healthcare**

This book is about using our healthcare resources to buy the most health for the most people. Buying health and buying healthcare are not equivalent. We face a paradox of excess and deprivation. Some people get too much healthcare, including expensive but ineffective tests and treatments. Experts believe that between one-third and one-half of all of the services purchased and delivered by our healthcare system have no beneficial effect on patients [5].

The overuse of services has negative consequences for at least two reasons. First, excessive use forces the costs of healthcare to increase. In the US healthcare system, increased costs are passed on to employers, who pay most of the health insurance costs. As costs increase, many employers decide to discontinue coverage for their employees. The result is that the uninsured rate increases [6, 7]. Today, nearly 50 million US citizens are without health insurance [8]. In a kind of paradox, excess and deprivation are causally linked. Over-consumption causes insurance rates to rise, resulting in an increase in deprivation for the most vulnerable portion of the population.

The second reason excessive use is a concern in that exposure to medical care is not without risk. A report from the Institute of Medicine of the National Academies of Science suggests that complications of medical care are the third leading cause of death in the USA [9, 10]. Even though screening tests such as mammography seem very safe, there may be consequences. The United States Preventive Services Task Force does not recommend mammography for women before age 50 [11]. There is no evidence from major clinical trials to suggest that screening mammography before menopause leads to an extension of life expectancy [12, 13]. However, among women who begin mammography in their late thirties, as recommended by some professional societies, the chances are 1 in 3 that they will have a false-positive result by age 50 [14]. These false positives lead to painful and anxiety-provoking biopsies and can be quite threatening. There is considerable fear, anxiety, pain, and expense. Patient benefit is often minimal, and harm can be a reality.
Is More Better?

My personal attachment to the problems has come through an unusual course. I am a Ph.D. rather than an M.D. So, I approach the problem from a different angle than a practicing physician. However, I have a great deal of familiarity and empathy for the challenges facing medical practitioners. As a professor in a School of Public Health, I study health policy. I came to this position after more than 30 years as a professor in a medical school. During those years, I participated in nearly all of the courses in the medical school and the programs for training primary care physicians. The last 8 of the 30 years were spent as chair of a Department of Family and Preventive Medicine. Among other tasks, I had responsibility for the oversight of a substantial medical practice in an era when managed care became dominant in the medical landscape. Patients complained that they did not get all of the services they wanted, and frustration with managed-care companies became rampant. Why don’t those cheap companies get in line and pay for the services their insured patients deserve? Believe me, as a patient and a family advocate for other patients, I shared these frustrations.

An easy solution to our problems in healthcare is to recognize that healthcare is important and that we need to spend money for good service. Every medical specialty group lobbies for more coverage. We need more money for primary care, more money for specialty care, more money for the care of children, more money for the care of the elderly, and more money for the care of disenfranchised groups. In addition, we need more money for research, more money for allied health professionals, more money for community health centers.

But will more money heal the problem? The US healthcare system is the most expensive sector in the biggest economy in the history of the world. On a per capita basis, nobody approaches our expenditures. The UK spends only about $0.40 for each dollar spent in the USA, and more or less the same story holds in other developed countries: Belgium and Denmark spend only about $0.50 for each dollar spent in the USA, and Spain spends only about $0.33 [15].

What is our extra expenditure purchasing? One of the most important unexplored assumptions in healthcare policy is that greater expenditure will result in better health. We know from international studies that developed countries that spend considerably less on healthcare have about equal health outcomes. The health of nations is typically compared using measures of life expectancy or infant mortality. Even though the UK spends well less than half of what the USA spends per capita, life expectancy in the UK is slightly greater than it is in the USA, and infant mortality rates are slightly lower. Among thirteen countries in one recent comparison, the USA ranked twelfth when compared on sixteen health indicators [16].

Within the USA, there is considerable variability in healthcare spending. For example, using data from the Medicare program, the per capita spending ranges from a low of $2,736 in Oregon to a high of $6,307 in Alaska. State-level data are also available on the average quality of healthcare. Quality is typically
defined as adherence to defined standards of patient care. For example, it is possible to estimate the extent to which physicians adhere to defined patient guidelines. There appears to be little association between per capita spending and the quality of care patients receive [17]. Spending more does not buy better quality of care. In fact, states that spend more per Medicare recipient appear to have lower quality care. In medical practice, specialists are more expensive than primary care doctors. The states that spend the most are those with a higher percentage of medical specialists and fewer primary care doctors [17]. Some analyses show that areas that have more primary care doctors, not more specialists, have better health outcomes. Adjusting for socioeconomic status does not alter this finding.

What Is Wrong?

Fixing problems in healthcare may sound easy. Hundreds, if not thousands, of politicians, policy experts, government officials, academics, healthcare professionals, and even authors have offered solutions. However, despite the application of the very best minds and the expenditure of an ungodly amount of money, we have made remarkably little progress in the quest to fix American healthcare. A major premise of this book is that we have failed because we have been guided by some basic beliefs and these beliefs may be incorrect.

In the following chapters some basic notions will be examined. Some of the questions to be considered include:

- Will improved diagnostic technology result in better population health?
- Must all disease be eradicated?
- Is more healthcare always better?
- Should we promote public-health screening for diseases such as cancer and heart disease?
- Is early detection the best approach to preventive medicine?

With some qualifications, this book takes a controversial position: The answer to each of these questions is “no.” The justification for these conclusions is explained in the next few chapters. To set the stage, though, a conceptual model is offered first. The model challenges the belief that modern medicine is well equipped to eradicate chronic diseases such as cancer and heart disease. We have failed to recognize that most important chronic diseases evolve over decades in a person’s body. By the time they come to medical attention, they are well-entrenched and not subject to cure. Treatment may alleviate some of the suffering from these conditions, but care may also cause problems that harm our overall level of well being.

Few of us will escape chronic illnesses, but the good news is that our lives may be unaffected by some of these conditions. In fact, we might be better off not knowing about some of the disease that is already established within our
bodies. And looking for these problems may not be a fruitful exercise. Some diagnoses lead to unnecessary treatment. Furthermore, aggressive programs to find new disease might have other public-health consequences. When we use public-health resources for one purpose, we give up the opportunity to spend money that could have achieved better outcomes for another problem. This problem will be considered later in this book. Finally, the implications of the model for public health and its relationship to actual medical decisions will be explored. In the final chapter, I offer methods for patients to become better consumers of their own healthcare.

In summary, the goal of this book is to offer a different way of thinking about problems in healthcare and preventive medicine. A few disclaimers are necessary. Many intelligent and well-informed people will disagree with some or even all of the basic premises. That is expected. If the book is not provocative, I will not have achieved one of my primary goals: to provoke thought and positive change. Second, I can say with certainty that these ideas warrant additional research. Scientifically conclusive tests are not currently available for many of my assertions. However, the evidence supporting the concepts is quite substantial. Wherever possible, I support my assertions with the best contemporary research evidence I can find. And finally, I do hope that the ideas offer enough challenge to open new and different conversations about and explorations of healthcare and preventive medicine policy.

References

Chapter 2

The Disease-Reservoir Hypothesis

Chapter 1 began with the story of Sally, a 77-year-old woman who had been diagnosed with ductal breast cancer. Sally received aggressive treatment and went on to live a life free of breast cancer. She also suffered from the consequences of the treatment. Not everyone believes that Sally required treatment, but few would advise her against taking action. The suggestion that Sally consider foregoing treatment disturbs many people. However, we do need to ask, what would happen if she consumed, and if we as a nation consumed, less medical care? The question is deceptively simple, but the answer maddeningly difficult.

To attempt an answer, it is best to begin at the beginning. The purpose of healthcare is to improve health. Health outcomes can be defined in terms of only two measurements: quantity of life and quality of life. A successful treatment is one that makes people live longer and/or improves quality of life [1, 2]. If a treatment neither extends life nor improves its quality, we must challenge whether it has benefit. Many people express their level of wellness in terms of numbers given by common medical tests, such as blood pressure, low-density lipoprotein (LDL) cholesterol, or blood sugar. These numbers have earned their importance because they are related to the chances of having a shorter life or of developing a disability or illness in the future. Other biological markers are less clearly related to meaningful clinical outcomes. Biomarkers such as measures of blood chemistry, cholesterol, or genetic typing should only be considered important if they are correlated with either quality or quantity of life.

It is becoming increasingly clear that there are also huge reservoirs of undiagnosed disease in human populations. As diagnostic technology improves, the healthcare system will be challenged because these common, previously undiagnosed problems will be identified in many individuals who may not benefit from treatment because their length of life or quality of life will never be affected. The problem has been fiercely debated in relation to cancer-screening tests such as mammography and prostate-specific antigen (PSA) [3, 4].

According to the American Cancer Society, screening and early detection of cancers save lives [5]. It is believed that there is an undetected reservoir of this disease that might be eliminated through more aggressive intervention.