

Preface: Which Persons Have Which Outcomes?

Mammography became popular as a screening tool for breast cancer in the 1970s after a study in New York suggested a 30% decrease in breast cancer deaths with its use. Although the original study showed a benefit for women older than 50, the National Cancer Institute encouraged women to obtain mammograms after the age of 35. It was believed if breast cancers were found earlier on mammography, then treatment would be more successful and more cures would result. It was assumed that most breast cancers would be found through this screening.

However, mammography finds many areas that are not breast cancer but cause great concern. Subsequent needle biopsies, follow-up mammograms and surgery, despite a benign diagnosis, do not quiet the anxiety or allay the fears that the same process won't be repeated in a year's time. Mammography can find early breast cancers which might be so early that they are never really a threat to a woman. A negative mammogram does not prevent a cancer from occurring before the next appointment. Similarly, blood tests and genome studies only yield small probabilities of cancer in a given woman and do not really direct treatments, relieve stress, or allay fears.

In the late 1980s the American Cancer Society and the National Cancer Institute encouraged women to seek mammography, beginning in their 40s and annually. There was a subsequent rise in the diagnosis of breast cancer, as though the rate of cancer was increasing. Many of the newly diagnosed breast cancers were carcinoma-in-situ, meaning non-invasive breast cancer. In 2002, the United States Preventive Services Task Force, an independent advisory body to Department of Health and Human Services, recommended that women have annual or biannual mammograms beginning at age 40. In November 2009, the same Task Force recommended that breast cancer screening using mammography begin at age 50 and that mammograms should be obtained every two years.¹³⁹

Medicine and public health have conducted innumerable studies and still there is confusion regarding mammography. A national study in Norway stated that there were few benefits from mammography screening; the reasons related to finding early cancers on mammography that really would not threaten a woman while the radiation induced cancers balanced early detection. A comparable national study in Sweden stated that mammography was clearly beneficial: that there would be one fewer death in populations greater than 50,000 if regular national mammography is undertaken. But the reduction in cancer deaths did not take into account geographic differences in study populations or that the three major urban regions in Sweden had higher cancer rates not accounted for in the report.^{104,128}

The former director of NIH was quoted in a newspaper that mammography would save money but not lives. The former head of Medicare hoped that we would learn from the mammography controversy and avoid repeating mistakes. Mammography has been offered for nearly 50 years and millions of x-rays taken, yet a recent article in the New England Journal of Medicine entitled “Lessons from the Mammography Wars” recommended that, “clinicians should defer to an individual patient’s preferences.”¹⁹⁴

If national studies have conflicting results, if public health agencies appear confused, if physicians are uncertain, how can an individual make an informed decision? Mammography is meant to screen for early breast cancers which are then cured through early detection. But it is not known how many found breast cancers are true threats to a woman; many mammographic findings are non-invasive malignant appearing cells of unspecified true malignant potential. In a very few women, the radiation of mammography may do more harm than good.

Breast cancer is not uniform across ethnic and racial groups; outcomes vary based on socioeconomics, lifestyle, and behaviors; education and environment may be of influence. How can an individual woman make a determination?

The problem is the current state of medical information concerning health, chronic conditions and aging. Although much information is presented in convincing form, the reality is often something else. Much of health and medical information is neither black nor white, but resides in the center of an information distribution curve, the grey area in-between well and sick, positive and negative. Conclusions of cause and effect are often based on low probabilities and rare events. Medical records are stored on database servers and retrieved on personal computers, but the information is still that of the physical era of paper with handwritten notes and lab tests.

Before the digital era of electronics with personal computers and international internet-networks, asking individuals a few questions and keeping records by number code in paper files was fine. There were few choices. But there are other choices today, to allay the troubles of individuals and prevent the bankruptcies of populations. What is needed is a vast backbone, a health care infrastructure consisting broadly of health and deeply of medical information, which is recorded through personal sensors, analyzed on supercomputers, communicated by internetworks, accessed through personal computers. This book is about that infrastructure: who will use it, what problems it solves, where it will be used, why it chooses its designs, and how it works.

Healthcare is in crisis now, no viable health system exists. The cost of care will bankrupt every modern economy even with present infrastructure; the quality of care is not adequate for chronic conditions that dominate the aging populations. But *there is a way out right now!* There is a new healthcare infrastructure using existing technologies that can support a new health system for individuals and populations.

Healthcare is an information problem; it needs an information solution using modern information technology. The old technologies of medical records do not suffice, but the new technologies of internet services do. There is a middle way for salvation, in-between the electronic medical records of the past and the personalized genomic medicine of the future. It gathers information from all the sources affecting personal health: from the bodies of individuals, from societies of populations, from everyday life.

Large-scale health data sets from millions of persons are necessary to properly evaluate the quality of medical care and outcomes. Current methods do not measure up to daily usage across all of America, as shown by numerous examples where a treatment was widely used before science showed that it might cause more harm than good. If national data sets existed, these treatments would have been used only by populations who would properly benefit.

The new healthcare infrastructure will record these personal health records from every individual and correlate each longitudinal record across the whole population. The computer analysis will produce clusters of persons with similar measurements of health status, who can be advised to similar managements of health care. That is, the measurement discovers which persons have which outcomes and the management uses this knowledge to provide efficient healthcare. This process will provide enough information for decision making to effectively manage provider care and manage patient expectations.

Measure all of the features for all of the persons to give them what they need when they need it and no more!

PROBLEM

Dr. Sarah Gordon's office, October 14, 2010. Mrs. H. Harrison and her daughter, Linda, have an appointment to review Mrs. Harrison's mammography report. Dr. Gordon leans back, glancing at the copy of her medical journal with lead article stating mammography has some value but only in certain conditions. Dr. Gordon is well aware of the change last year in US national guidelines, raising the screening mammography age to 50, from 40. Or was it from 50 to 40? Dr. Gordon sighs.

"Hello, Doctor."

"Hi, how're you doing?" Dr. Gordon asked.

"Fine," Mrs. Harrison replied, "but I still have that vague pain in my right breast."

"I see. Well, that should get better. Ah, I have your mammogram report and we should go over the findings," Dr. Gordon said clicking on a computer screen on her desk.

"Is there a problem?"

"Not really a problem. Just something we have to look at further."

Mrs. Harrison looked up, worried. "You see, there are some faint findings on the mammogram of the left breast that suggest we..."

"But the pain is on the right," Mrs. Harrison interjected. "I know," Dr. Gordon replied, "but there are these very small calcifications on the left. Here, let me show you." Dr. Gordon turns the computer screen so all three can see the digital mammography films on the screen.

"I don't see anything," Mrs. Harrison queried. "Mom, it's your eyes," Linda cut in. "It's those white dots. Over there." She pointed. "You've been so stressed since Dad became ill, and your diet just isn't healthy anymore...."

"Yes. It means you need a biopsy."

"Is that surgery?" Mrs. Harrison asked. "No, not surgery. A needle biopsy done with mammography as a guide." Dr. Gordon answered.

“Is it cancer?”

“Probably not, but we have to do a needle biopsy, get some cells, to prove that those tiny spots are benign.”

“If it’s not cancer, then why do a biopsy?” Mrs. Harrison sat forward. “Just to prove...”

“Is this one of those cases where mammography isn’t much help? Like I heard on the news last...” Mrs. Harrison shifted to her right.

“No. But...”

“I had a mammogram last year. I get one every year.” Mrs. Harrison leaned forward.

“If it’s cancer, do I need a mammogram?” Linda asked. “There’s not much cancer in our family. If Mom has cancer, I heard I should be screened with a blood test, the BLAC...”

“BRCA,” Dr. Gordon corrected. “No, you don’t need that...”

“Why not?” Linda asked.

“Maybe I should get an MRI. Our neighbor has breast cancer and she had an MRI. It was the most sensitive test available. Why don’t I get an MRI?” Mrs. Harrison shifted to her left.

“You don’t need an MRI. We just need to do a needle biopsy and get a few cells...”

“From the right or the left?” Mrs. Harrison was anxious.

“The left. Look, I don’t think this is anything. But we need to do a biopsy, just to be sure. Don’t worry, everything will be fine.” Dr. Gordon sat back.

Mrs. Harrison gets up to leave, looking very upset.

“Please sit down. The data is available. Let me tell you how we can get all the information I want and you need to understand what to expect.”

“What information?”

SOLUTION

Every day, millions of persons search on Google, share on FaceBook, shop on Amazon. Internet services show the way to measure everyday health for all individuals, by analyzing the trends of cohort populations within geographical regions. This leads to a healthcare infrastructure that will support viable healthcare, acceptable quality at acceptable cost.

For example, Google Flu Trends offers a service assessing risk of catching the flu, using internet queries from their search engine. They worked with the Centers for Disease Control to adapt this technology from their commercial trends service for determining product popularity. The Google system itself automatically collects information from millions of widely distributed sources, before indexing this to support rapid search capability at their custom supercomputer data center.

The mobile phone and the personal computer allow independent access and input. The Internet facilitates communication and collation of enormous stores of data.

Supercomputing enables engineering of significant patterns and guidelines from disparate sources. Health, aging and chronic conditions require a new infrastructure that assembles parts already present and information already produced. It is time that health-care and the health of individuals moved beyond the age of paper records, flat files, and limited datasets to a comprehensive backbone of healthcare infrastructure.

The national healthcare infrastructure will measure daily health of all individuals and extrapolate this to the health of populations to provide the data necessary to manage the nation's health. It will ensure universal access for universal healthcare, by reaching all populations with appropriate interfaces. Seniors can be reached with phone calls to their homes, students with text messages on their cell phones, baby boomers with web forms via their personal computers. Even the uninsured and under-served can participate with inexpensive devices on ubiquitous networks.

For the individual, health care infrastructure brings current analysis and meaningful comparison. Cohorts of similar individuals can compare themselves and measure progress as they modify lifestyle and behavior to move to a healthier cohort. Education becomes an integral part of the process, illuminating the path. Their patient clusters share characteristics which can be modified; diagnosis fades as guidance takes over for providers to help manage patient lives.

For the population, public health finally has the means to fulfill its mission. It can track and monitor, work toward early identification of emerging problems. Interventions can be matched to similar populations with an outlook toward common goals. Resources can be apportioned for greatest benefit. Public health information merges with that of personal medicine; databases analyzed and sorted depending on need, not availability. Common information infrastructure for health care supports all participants at all levels, each taking what they need proper to the task.

Indexing the nation's health will use 21st century technologies to solve 21st century problems of health, aging and chronic conditions. Different groups of people in different populations respond to health, aging and treatments in different ways. The interactions with individuals will generate measurement of populations, as the input for massive data mining on large-scale supercomputers. These new information technologies will gather the data necessary to support healthcare infrastructure for viable healthcare.

Measuring health is like tracking flu; it is time to use the strongest private technologies for the greatest public good. In the near term, modern Information Technology can revolutionize Public Health and Personal Medicine, bringing patient treatments into a unified whole.

The principles of healthcare infrastructure discussed in this book are just as relevant today as in the historical examples. The evolution of infrastructure in communications from telegraph into telephone may seem ancient history, but the evolution of landlines to cellphones is occurring right now. Cell phones already dominate landlines worldwide, even if mobile devices with wireless connections are not considered. Some populations have few landlines, where the ubiquity of mobile devices will help them achieve modern healthcare infrastructure.



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