

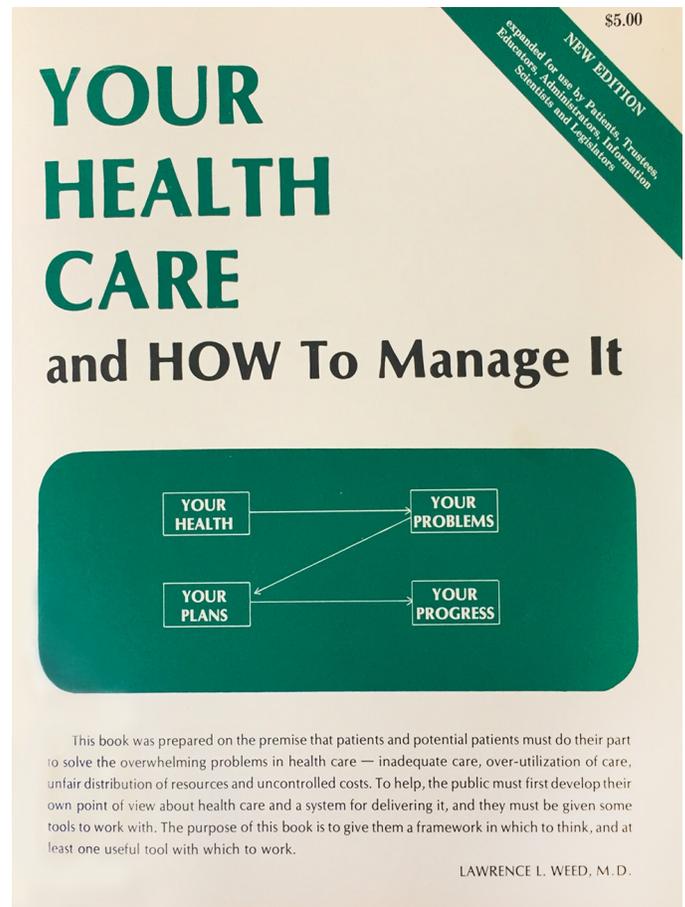
'The patient must have a copy of his own record'

By Dave deBronkart | October 11, 2017

When the legendary Larry Weed – physician, entrepreneur, and pioneer of the EHR – died June 3, much was written about his vision and his irascible personality. I met Larry at his home two years ago and wish I'd known more about him then, because I recently discovered the most in-your-face declaration he ever made.

"Responsibility for health care rests in the patient's hands," he wrote, "because that is where the knowledge of and control of the variables lie Therefore: The patient must have a copy of his own record." (Emphasis added.)

Weed wrote this in 1975, well before the proliferation of EHRs, in his book "Your Health Care and How To Manage It." Not one of the essays and obituaries I've seen mentions that core principle: Nobody – not a soul – is in a position to stay on top of a patient's information as well as the patient. The model is so essential that Weed made it the cover art for the book. Here's a close-up:



YOUR HEALTH CARE
and **HOW To Manage It**

YOUR HEALTH → **YOUR PROBLEMS**
YOUR PROBLEMS → **YOUR PLANS**
YOUR PLANS → **YOUR PROGRESS**
YOUR PROGRESS → **YOUR HEALTH**

This book was prepared on the premise that patients and potential patients must do their part to solve the overwhelming problems in health care — inadequate care, over-utilization of care, unfair distribution of resources and uncontrolled costs. To help, the public must first develop their own point of view about health care and a system for delivering it, and they must be given some tools to work with. The purpose of this book is to give them a framework in which to think, and at least one useful tool with which to work.

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That logical, sensible flow brings to mind something my primary care physician, Danny Sands, M.D., has said for years: "How can patients participate if they can't see what I see?" In fact, the model Weed created more than 40 years ago predicts many of the challenges we face in healthcare today – and points to data as the obvious solution. Let's walk through it:

1. "Your Health"

A care encounter typically starts when a patient identifies a problem: a symptom that wants attention. Then, medicine works its programs to get that problem addressed.

In his book, Weed defined this phase of treatment, from the caregiver's standpoint, as "collecting information." He called for the use of a "problem-oriented medical record": a database that would include patient history, labs, and other information.

But information needs to flow both ways. Today, patients have access to a ton of medically useful data that wasn't available, or even measurable, a few generations ago.

Thanks to technology, today's patients can sometimes know more than their doctors. Think of arrhythmia patients taking their own EKGs with the Kardia mobile app. How's that for an inversion of power?

In his book, Weed wrote, "The patient is aware of and has control over more ... variables than anyone else. The physician goes to medical school and tries to learn text-book averages about many diseases. The patient knows many things that the disease does to him; the facts are his with no formal education at all."

In other words, whose health is it, anyway? Who gets to say whether there's a problem?

2. "Your problems"

Weed defined this phase of treatment, for caregivers, as "deciding what's wrong." "You and your physician must set overall goals and goals for each problem together," he wrote, "and you must constantly keep in mind the expense to society and the danger to you of over-utilization of medical care."

That's not how healthcare usually works today. Traditionally, the doctor has defined whether a patient has a problem, based on literature and expertise: "Your A1c is too high." "Your creatine is too low." But what if I don't mind some condition, and don't consider it worth treating? What if I don't trust the medical literature? What if the condition isn't bothering me, but the treatment is? What if it's hard to get to the treatment facility, or it's not worth the cost?

Statins are a great example of this: The side effects are so considerable that many patients choose to drop treatment. Physicians don't like this turn of events. So who should decide whether the benefits are worth the pain?

I'd argue that the patient – not the doctor – is in the best position to set priorities, on his or her own terms. I knew a man for whom the top priority for his kidney cancer was to minimize fatigue, because he was primary caregiver for his wife, newly diagnosed with breast cancer.

This is foundational, because if the patient and clinician don't agree on a treatment goal, then we have no care team, and things are surely not going to go well.

3. "Your plans"

From a caregiver's standpoint, Weed defined this phase of treatment as "Figuring out what to do."

But how does best care change when patients have information, compared to when we don't?

Choosing Wisely, a project run by the ABIM Foundation and Consumer Reports, urges patients to ask their providers detailed questions about their treatment plans: Whether a certain test is needed, whether other treatment options are available, how much it will all cost. (I was involved in discussions that led the foundation to partner with Consumer Reports because of the organization's credibility, trust, and reach.)

Ultimately, this all goes to the question of how we define "value" in healthcare. In the current paradigm, driven by government reimbursement programs and fee-for-service structures, value is what the system says it will pay for: the cost of achieving outcomes that the provider deems proper.

But in the arriving consumerist era, as patients bear more of the costs of healthcare themselves, it's patients – the ones with the problems – who will decide what we think is valuable, on our own terms. Inevitably, that will mean we sometimes decline proposed treatments, as some of us are doing now.

When the ultimate stakeholder starts to define value, the change is profound – so much that it affects the core of medical practice: "Who's in a position to know what's important?" That's why it makes the people currently in charge feel a little bit uncomfortable.

4. "Your progress"

This is the phase of treatment Weed described, for caregivers, as "follow-through." And it gets to the heart of the question of power in healthcare. Who gets to say when treatment is done and the patient is all better? If my doctor says I'm finished, but I still feel miserable, whose opinion holds?

In August, I spoke at a "cancer survivorship" workshop at the National Academies of Science, Engineering & Medicine. Believe me, there are patients who say they were not all better when their doctors said, "Go home." (Prediction: Someday this will happen to your family.)

But the system today generally focuses on doing what it does, without asking why, much less whether the outcome is optimal.

That's one reason why patient needs can't be served by occasional visits – it demands a continuous exchange of information. But this is hindered by an industry that wasn't designed for the needs of the customer – and, in recent years, by EHRs that too often stand in the way.

Weed recognized this danger back in 1975, shouting (in all caps!) about the "silo" problem we still hear about today. Providers, he wrote,

ARE NOT NATURALLY MOTIVATED TO ASK QUESTIONS AND STATE PROBLEMS FROM THE PATIENT'S POINT OF VIEW. THEY CONTINUALLY SEE THINGS IN TERMS OF THE WAY THEY WERE TRAINED AND THE SPECIALTY THEY ENTERED.

This gives providers the skill and drive to solve a problem in their area of expertise once it's presented, he wrote, but not to regard the issues – and set priorities – from the patient's point of view.

Let patients help

If you accept Weed's framework – that health is my problem, and it's my responsibility to help manage it – then there's no justification for keeping me uninformed. To withhold information from me is to cause a shortfall, or create what Weed called, in his book, "crippling dependency states."

Yet patients still face foot-dragging from many medical organizations. At the Connected Health conference last fall, Yale cardiologist Harlan Krumholz told the crowd about a health system CEO who said he doesn't want patients to take their business elsewhere, so "Why would I make it easy" by giving them access to the data from their charts?

We can do better by letting patients and families help physicians determine the best course of care. This all was glaringly obvious to Larry Weed in 1975. Why can't it be the basis for healthcare today?

Dave deBronkart, also known as "e-Patient Dave," is a frequent writer and speaker on the patient experience.



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