# Restarting at the Base of the Pyramid

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Imagine for a minute that you had a car and its transmission would not shift gears, but you are on your own and, without it, you can't get groceries or go to work. The nearby garages – if you are lucky enough to find one – can't help for days. When you call an independent transmission mechanic, you learn the mechanic's earliest availability is three months hence, and a garage must request that. What's worse, the mechanic notes that the car's symptoms indicate you will need a new transmission – and the factory has a seven-month production backlog. That happens every day to patients seeking medical care.

For decades, we and many other professionals from a spectrum of disciplines have attempted to influence government and the health system to perform assessments of health services to make them more available. Concerned experts from Epidemiology, Health System Management, Health Informatics, and many other fields have noted that the needed assessments of the effects of medical actions are absent without leave. Without them, our health system operates in the dark. Government-level organizations have attempted assessments by documenting proxies, rather than actually demonstrating the benefits and harms of interventions. One example is the use of readmission to hospital as a measure of the effectiveness of a previous admission.

Those who are engaged in large data analysis of health system data try to work with whatever data is available and therefore produce evaluations of interventions whose results are dependent on specious underpinnings. The adage of GIGO applies! Seldom is the data available that would permit quantitative documentation of the patient's status before during and after treatment, capturing patient outcomes in terms of valid physiological, functional or even overall clinical state. The upshot is that we often do not know where the patient started, what was done, or if it helped or harmed the patient.

*If we accept the situation as is, on what basis can we justify our spending for health services?*

Countless articles, books, organizations, conferences and every other means of information exchange and influence applied to government-level organizations have failed to impact the situation. Those calling for change are "voices in the wilderness", passively ignored. Here we ask something that has influenced our behavior over the last seven years: is a top-down approach simply an ineffective one?

If, as is apparently the case, clear, coherent, cogent consultation has not worked, are we merely "doing the same thing over and over but expecting different results"? Dr. Einstein defined this as insanity. Perhaps it is time for us who cry to the upper echelons to change our mental status.

Over the last seven years, we have produced a compendium of books that empowers a new approach to solving this strategic societal disability of not fully knowing what we are doing or what its results are. We have produced a manual that supports changing the health system from the **bottom-up**. We have worked with the operant hypothesis that patients can morph into effective consumers of health care, who can demand they understand proposed interventions, their purpose, and their consequences.

This approach has worked in the domain of Consumerism, so it is credible. It has led to most of us reading reviews and shopping around both physically and via the web. Especially during economic constraint, this rises from optional to required. Constraints on the availability of money seem to juice up a consumerist attitude.

If we recognize that we are in a position that the available or plausible funding cannot properly address our health needs, would a consumerist approach to health care possibly work?

There are many reasons why it should. We live at a time of long wait times to see a primary professional. Those wait lines can be enormously longer if we need access to a specialist – ophthalmologists and orthopods seem to be endangered species! But they aren't! There just are not enough of them in the right places. Even worse is accessing a mental health professional – many resort to privately-paid services, and even they are hard to access!

When one actually gets to see the appropriate clinician, then there is the delay in virtually all types of specialized investigation, such as MRI, CT and every other modality. When one gets through all of that, and has a diagnosis in hand, then there is the wait for surgery, which can be months or years.

We treasure our health system, but it has meant that many people live in a Care Desert! Why does this viscous process for getting care exist? There is more than one reason, but poor, inadequately-informed planning, and the availability of funding are near the top. We already spend around 12% of our gross domestic product on health care, and what government funds is not complete…there is more to it: the addressing the determinants of health, like nutrition and housing. Of course, another reason is the availability of trained professionals, but that also is at least partly due to funding constraints and funding-influencing planning.

So why not just spend more? At some point, taxpayers will not consider that that affordable. It may, in fact, be inadvisable. It isn't just <u>how much</u> we spend; it is <u>on what we spend it</u>! How much of what we spend is sufficiently effective to justify more spending and does not cause further health problems?

Though comparing health care to manufacturing might offend most of us, how many manufacturers of a widget would survive if the widget did not work, or breaks down quickly, or damages the machine that needs it? While true that some companies get away with this, for a little while, consumerism has significantly impacted people's buying. The company would soon be in the rear-view mirror and bankrupt. On the other hand, how many companies would invest in a new manufacturing process if they did not know the performance of the current one, or if the new one would be better? Again, some might, but not for long.

What is true of manufacturing and is common sense, is that the assessment of the quality and acceptability of a process or product is crucial. However, this does not apply to how we develop, improve, expand and remove components of the health system! So, we drift towards the calamity of mass dissatisfaction or insolvency.

We are attempting to address this crisis. Our approach to empower people as healthcare consumers. We have produced a guide for everybody, particularly those already patients, giving them the knowledge, thinking skills, preparatory experience, and attitudes that prepare them to influence their own care. We have confidence that informed participants in care will influence those who plan, deliver, administer, fund and manage our health system to get their act together so they can make better decisions and improve the health system to address consumers' needs.

In plain English, with many stories and with a bit of humor, we have constructed a 'How To' book that prepares people to ask questions, find information, seek responses and engage in sensible conversation with care professionals. The first volume's title is 'The Nature of Clinical Care: a Gentle Introduction'. It is

highly readable by ordinary people and will support a variety of patient education programs.