

Chapter 15

The True meaning of Patient-Centered Care

The challenging problems being faced in both Canada and the U.S. have been tediously enumerated. In the end we must ask: how much healthcare does one really need? Obviously this can only be answered by the individual. Patients who tell me how happy they are with their system routinely add, “Of course...I don’t go to doctors much.”

As previously mentioned, the largest percentage of the healthcare dollar is spent on children under the age of one and the elderly over 65. No mother is ungrateful for the care her premature infant received while on a respirator for 4 weeks in the neonatal ICU. You will not hear a 67 year-old man with a pacemaker, an aortic valve replacement and implanted arteries to bypass blockages in both legs bicker. He’s thankful for all the care and services he receives.

Patients seem to complain most about access to their care provider, followed by concerns about waiting for testing or a specialist consultation. This occurs both in the U.S. and Canada. However, by design those waits are much longer in Canada. Next on the list of complaints is the cost of medication, and the amount of time lost from work because of injury or illness. Somewhere down the line, quality of care gets mentioned.

Notice then that access to anyone (MD, NP, PA, UCP, office secretary, etc.) is what’s important. I have seen patients sharing their problems with the maintenance man swabbing the hallway corridor, with the volunteer filling their water containers and especially with the registration clerk in emergency or the doctor’s office. They don’t want to feel abandoned. “Is there anybody out there...anybody?” Someone who will listen patiently, smile knowingly and show compassion—or more appropriately—demonstrate *philanthropia*.

In *Blink*, author Matthew Gladwell discussed ‘The Power of Thinking without Thinking.’ To insure survival, human beings learned long ago how to make quick decisions about novel situations—a process called thin-slicing. Researchers have discovered that most patients who suffer an

injury due to physician negligence never file a lawsuit. However, patients sue when they feel personally mistreated by their doctor.

The most fascinating conclusion about thin-slicing and malpractice was that training, competence and the amount or quality of information given a patient did not influence whether a physician would be sued. The most consistent predictor was the doctor's tone of voice: "if the surgeon's voice was judged to sound dominant, the surgeon tended to be in the sued group...in the end it comes down to a matter of respect, and the simplest way that respect is communicated is through tone of voice."¹

A placebo is a drug or procedure that has no known therapeutic function, yet produces a beneficial effect. Placebo comes from the Latin *placere* 'to please'. Even in its definition, the Oxford dictionary assumes a placebo produces mainly a psychological effect. However, recent evidence has shown that one's beliefs can actually induce physiologic changes:

Placebos have helped alleviate pain, depression, anxiety, Parkinson's disease, inflammatory disorders and even cancer. Placebo effects can arise not only from a conscious belief in a drug but also from subconscious associations between recovery and the experience of being treated—from the pinch of a shot to a doctor's white coat. Such subliminal conditioning can control bodily processes of which we are unaware, such as immune responses and the release of hormones.²

Even before I went to medical school I did research in leukemia at Roswell Park Memorial Institute—a prominent cancer hospital in Buffalo, New York. I was in awe of the physicians who could deliver terrible news to patients in such a compassionate and positive way that they and their families always remained hopeful.

¹ Gladwell M. *Blink*. Little, Brown and Company, New York, 2005: page 43.

² Niemi, Maj-Brit. "Placebo Effect: A Cure in the Mind." *Scientific American*, Feb 25, 2009. www.scientificamerican.com/article.cfm?id=placebo-effect-a-cure-in-the-mind

We've all heard the stories of Uncle Joe who lived with stomach pain for many years, yet died 2 weeks after "they cut him open, found cancer all over, closed him up and said there was nothing more they could do." His rapid demise would be explained by the tumour being "exposed to the air." Perhaps its more reasonable to assume that he could no longer ignore the gravity of the problem and simply gave up.

I have often seen comatose patients 'wait' for family members to arrive—or leave—before departing. A loving wife sits by her husband waiting for him to breathe his last. As she gets more exhausted through the ordeal, I reassure her, "He's not suffering."

"How long can he go on like this?"

"Only he can make that decision. Maybe he doesn't want to cause you pain, so he keeps holding on."

I have given her permission to leave his side, and given him permission to make his transition in peace. Incredibly the patient dies shortly after the family departs.

There are certain journeys we must make on our own.

Everyone has experienced this phenomenon. I spoke to a friend who sat by a 92 year-old old woman who had a stroke and was totally unresponsive. We all respected her wishes for no life-saving measures. The friend said, "She was never sick. It's funny, her sister whom she hadn't seen for 20 years had just visited from Germany."

"When did she leave to go home?"

"Yesterday," she says, wiping a tear from her cheek, "It's almost as if she had said goodbye."

These aren't coincidences.

I'm not intimating that medicine is some shell game. However, quality of care and the response to treatment are dramatically influenced by psycho-emotional factors. When I mentioned earlier that the doctor-patient relationship is dead, I was not lamenting its demise. It has evolved into someone-who-cares-patient relationship. Perhaps this is the way it's always been. **BURWELL?**

In a study comparing doctor visit times, patients were asked about their expectations. They wanted the doctor to provide information about the biomedical aspects of their problem, the meaning of their symptoms,

and the seriousness and expected course of the problem. More importantly, they wanted help in dealing with the psychosocial aspects of their illness: with their on-going anxiety and by having the doctor explain and show support for their emotional problems.³ No wonder there is so much dissatisfaction with modern healthcare.

A *New York Times* article stated, “Medicine is rapidly changing in the United States from a cottage industry to one dominated by large hospital groups and corporations, but the new efficiencies can be accompanied by a telling loss of intimacy between doctors and patients. And no specialty has suffered this loss more profoundly than psychiatry.” Patients who used to be admitted for months of daily counseling are now discharged after a few days with new or adjusted medications. 68 year old psychiatrist Dr. Donald Levin lamented that he no longer could spend time talking with or counseling patients, “I had to train myself not to get too interested in their problems...Now I feel like a good Volkswagen mechanic.”⁴

The need for communication and compassion in medicine has changed little throughout history. The original hospitals were healing sanctuaries—places the sick would go for rest, nutrition, sacrifice, prayer and treatment by priests. Contrary to the view that a placebo only produces a psychological benefit, the psyche and its influence on the body is real. Most of us proudly boast that the consciousness of mankind has “evolved” over time, yet the psyche continues to exert its influence according to specific laws or patterns:

These laws do not change, although different ages and different parts of the world call them by different names. On a primitive level people are afraid of witches; on the modern level we are apprehensively aware of microbes.

³ Deveugele M, et al. “Consultation length in general practice: cross sectional study in six European countries.” *BMJ*, 325 (7362): 472, August 31, 2002.

www.ncbi.nlm.nih.gov/sites/ppmc/articles/PMC119444/

⁴ Harrs, G. “Talk Doesn’t Pay, So Psychiatry Turns Instead to Drug Therapy.” *NYTimes*, March 6, 2011, p A1.

www.nytimes.com/2011/03/06/health/policy/06doctors.html?pagewanted=1&_r=2

There everybody believes in ghosts, here everybody believes in vitamins. Once upon a time men were possessed by devils, now they are obsessed by (facts and ideas).⁵

Despite the trend in modern medicine to specialize and sub-specialize, humans are not made up of separately functioning physiological and anatomical compartments. The mind and body are so completely intertwined, it is impossible to separate the psychosocial from biomedical aspects of health and sickness. In fact, even the difference between what constitutes health versus sickness is relative and relational.

When discussing pain for example some people can lie on a bed of nails, or walk on a deformed broken ankle, yet others scream when you touch their shoulder: "...but doctor you don't know how much pain I'm in." To solve this problem, every medical training program teaches the quantified pain-scale. Unfortunately its usefulness is limited because patients often emotionally respond when questioned, "It's a 20 out of 10!!!"

Although the terms illness and disease are used interchangeably they do not mean the same thing. The patient defines his experience of discomfort as illness: what is bothering him, what symptoms he has, or why she seeks medical attention. Illness exists solely through a patient's awareness. Disease is a disorder of structure and/or function of an organ system within the body. It is possible—in fact probable—that someone has a disease for a period of time without being consciously aware of, or experiencing it. Illness is subjective and oft-times unverifiable. Disease is objective, able to be measured, and once it takes hold, it is obvious to everyone.

The following is a typical interview. A patient complains of feeling terrible:

"How do you feel terrible?"

"I'm weak and dizzy."

"After working all day, you drove to the clinic, and you look fine sitting in that chair, talking on your cell-phone."

⁵ Jung C. "Eastern and Western Thinking," in *The Portable Jung*. Edited by Joseph Campbell, The Viking Press, New York, 1971: p 493.

“...but I can’t concentrate—my head aches. It’s been hard to get up in the morning. I have no appetite.”

Searching for something objective I ask, “Since you’re not eating, how much weight have you lost? Have you missed any work?”

“I haven’t missed work and the strange thing is—I’ve put on weight.”

“How long has this been bothering you?”

“Over six months...”

Contrast this consultation with that of a patient who walks into the room with a swollen abdomen, his face is drawn and yellow. He complains, “I’ve been feeling weak and dizzy.” You look at the poor guy and after a few questions immediately refer him to the hospital. After he leaves, everyone in the office comments, “He looked ghastly.” In the hospital he’s found to be extremely anemic, jaundiced and riddled with cancer. He dies one week later.

These are everyday cases. Fortunately, the patient totally overwhelmed by disease before seeking care is less common.

Distinctions between illness and disease:⁶

Illness	Disease
Experienced by the patient	Diagnosed by the physician
Symptoms	Signs
Subjective	Objective
Unique to the individual	Replicable in others
Not directly verifiable or proven	Verifiable, measurable, obvious
Affects whole person, every system	Affects specific body parts
Feeling unwell, ‘...just not right’	Is unwell
Affects quality of life	Affects quantity of life
Responds to compassionate care	Removed, treated dispassionately
Cause of discomfort and suffering	Cause of death
Not merely an extension of disease	An inevitable cause of illness

⁶ Reading A, MD. “Illness and Disease.” In *The Medical Clinics of North America*, volume 61, no 4, July 1977: p. 704.

The table highlights the two paradigms of medical care: (1) the relief of suffering, and (2) the prolongation of life. Much of the dissatisfaction with modern medicine stems from the fact that healthcare systems are more interested in the treatment of disease and the prolongation of life. While patients obviously have this goal, they also place great emphasis on the relief of suffering—i.e. compassionate care.

It is particularly important that the physician realize that his own *disease orientation* is not always shared by the patient. The patient's primary concern is his illness. As self evident as this may seem, failure to appreciate it fully can easily lead to a great deal of unnecessary friction and misunderstanding. When the patient feels ill and takes himself to the physician, it is his *illness* that he wants the doctor to fix. In some curious way, however, when the patient consults the physician, the latter listens to his story and questions, examines and investigates him primarily for evidence of *disease*.⁷

The two paradigms draw the line between modern, western health care and traditional, eastern medicine. The distinctions are way beyond the scope of this book, but the two thrusts of medical care require some superficial mention of them.

In the opening lines of *Metaphysics* Aristotle wrote, "All men by nature desire to know." He was most interested in the questions: why and how? These are still signposts that guide travelers along the road of western science. In our tradition, disease is defined as the disruption of cellular function with a definitive, measurable and verifiable cause.

The eastern or traditional scientist seeks to understand the interrelationship of man with the cosmos. Simplistically, this world moves like a pendulum, always in search of balance—the median, the norm—yin versus yang, health versus dis-ease. The problem is: perfect balance means inactivity and stasis—concepts incompatible with a living organism. Twenty three centuries ago Taoist philosopher Lu wrote, "The operations

⁷ *Ibid*, p 705.

of heaven are profoundly mysterious. It has water-levels for leveling, but it does not use them. It has plumb-lines for setting things upright, but it does not use them.”⁸

The stage was set long ago for the continuing conflict between patient expectation and healthcare practitioner capability, between scientific determinism and holistic therapy, between treating illness and relieving suffering versus measuring disease process and prolonging life. Is there any way to reconcile these differences?

Take charge of your health

Every day patients tell me they did some research on the internet. I believe that with proper use, the internet will enable patients to take the initiative, and encourage them to become true partners with their healthcare practitioners. However, this requires two indispensable things: (1) a trusted source of information, and (2) a filter of knowledge.

Abraham Lincoln wrote, “I am a firm believer in the people. If given the truth, they can be depended to meet any national crisis. The great point is to bring them the real facts.” Individuals have an intimate knowledge about their illness: they are the ones who experience it, they know how they feel, and just as importantly, they have the time to research their symptoms. I’m amazed at the accuracy of diagnoses that patients present to me. It is apparent that the most important solution to the current healthcare crisis is for patients take control of their own health, and this is the real definition of patient-centered health care.

There is one persistent defect in this approach—the need for a filter of knowledge. A young lady came to see me complaining of chest pain. Before I was able to delve into her symptoms and examine for signs, she told me she was scared because after researching on the web she had concluded that the source of pain was either a lung tumor, or angina. I responded that while these diseases can cause chest pain, they were both highly unlikely in an 18 year-old, non-smoker.

⁸ Lu. “Spring and Autumn Annals.” Quoted in Needham J: *The Great Titration: Science and Society in East and West*, George Allen and Unwin, London, 1964: p 324.

Anxious parents frequently ask, “What temperature is dangerous for my child?” Unfortunately I tell them that the answer is not all-or-nothing. I have treated far more febrile seizures at 102° than 104° and I never had a child in emergency with a fever over 105° have a seizure. Also I have seen kids who had a seizure at 102° return with a temp over 104° and not seize. Once again this demonstrates the failure of precision in numbers, data or testing.

Patients frequently ask, “What is my ____level? When I tell them they usually ask what that means. They are seldom happy with “it’s normal” and they get upset with “it’s ok”—a term I use when the results aren’t normal, but the minor abnormality is insignificant. I have no problem with handing the patient a copy of his blood work or MRI scan. However, I don’t even know some of the nomenclature used by the radiologists and often skip to the conclusion. I envision the patient on the internet looking up and worrying about some insignificant abnormal findings that have nothing to do with his original complaint.

Information is not knowledge. In medical school it’s well-known that students repeatedly self-diagnose as they progress through the syllabus of diseases. Over time they develop the ability to sift through the labyrinth of symptoms. The lack of a sensitive filter will bring needless worry to patients, but more importantly will actually increase the costs of medicine.

This problem was highlighted years ago when total body CT and PET scans became available. The machines were so sensitive they found many asymptomatic lesions throughout the body that opened up a whole can-of-worms. What do they mean? And what should be done about them? It’s for this same reason that routine screening mammograms have fallen out of favor for younger women.

Don’t worry ladies you are not being singled out. The lack of specificity helps explain the controversy and confusion surrounding the Prostate-Specific Antigen (PSA) test. While it is elevated in prostate cancer, there are other conditions that will also cause a rise in PSA (remember the aforementioned d-dimer example). From the website of the National Cancer Institute: “Doctors’ recommendations for screening vary. Some encourage yearly screening for men over age 50, and some advise men who are at a higher risk for prostate cancer to begin screening

at age 40 or 45. Others caution against routine screening.”⁹ Sounds like a consensus to me.

Today over 30 million men in the U.S. have their PSA measured annually. Yet as Richard Albin, the scientist who discovered PSA in 1970, wrote in a *NY Times* op-ed piece observed:

Testing should absolutely not be deployed to screen the entire population of men over the age of 50, the outcome pushed by those who stand to profit.

I never dreamed that my discovery four decades ago would lead to such a profit-driven public health disaster. The medical community must confront reality and stop the inappropriate use of P.S.A. screening. Doing so would save billions of dollars and rescue millions of men from unnecessary, debilitating treatments.¹⁰

The other day a young man came in and told me his back got stiff and tired after standing all day at work. Although he has had this problem for a long time, he hasn't missed any work. On exam, he was a little stiff but could bend over fine with minimal discomfort and with no radiation of pain down his legs. Yet he felt he “needed some scans.”

In Ontario alone, it has been estimated that over \$24 million is spent on unnecessary CT and MRI scans. The scans carry a 60% false positive rate, i.e. show insignificant or unimportant abnormalities. While it seems obvious that rationing of healthcare occurs in Canada through long wait times, I agree that

Thousands of Canadians with severe back and neck pain face agonizingly long waits to see spine surgeons, only to learn they didn't need to go in the first place, creating

⁹ National Cancer Institute. “Prostate-Specific Antigen (PSA) Test.” www.cancer.gov/cancertopics/factsheet/Detection/PSA

¹⁰ Albin RJ. “The Great Prostate Mistake.” *NY Times*, March 9, 2010. <http://www.nytimes.com/2010/03/10/opinion/10Ablin.html>

mounting frustration and costing millions of dollars. The reality is that back pain is common and that high-tech tests ordered by doctors often find abnormalities that have nothing to do with the symptoms – but lead to a referral to a spine surgeon. The wait can be up to a year or more, and then the surgeon frequently has nothing to offer except advice to exercise, get physiotherapy or use back supports.¹¹

Once again we must ask: how much healthcare do you need? In this example, low back pain most often improves on its own (some times over months). For most people, if armed with a basic knowledge of body mechanics, symptoms will be reduced through activity and behavioral modifications that include stretches, exercises and relaxation techniques.

Summary

- Take charge of your own health.
- Beware and be aware of the most important caveat—utilize a filter of knowledge by consulting trusted informational websites or your healthcare professional, or by studying medical texts.
- Be very wary of the opinions or experiences of others: forget the adage ‘what’s good for the goose is good for the gander.’
- Know thyself.
- Heal thyself.

¹¹ Priest, L. “Canada’s costly spine-surgeon backlog.” *The Globe and Mail*, May 12, 2011. www.theglobeandmail.com/life/health/new-health/health-news/canadas-costly-spine-surgeon-backlog/article2020599/