Understanding Your Medical Mind: Decision Making Through Patient-Doctor Dialogue
Pamela Hartzband and Jerome Groopman, with Deborah Wallace

Seeing the System Inside-Out
Hugo Sax

Commentary
Manoj Pawar

I Have Never Been Here Before: The Nonlinear World of Cancer
Marilyn Herasymowycz and Henry Senko

Commentary
Emily Tilton

Change on the Scale of the Whole: Health, Peace, and Prosperity for All
Victor Garcia
The current state of health and healthcare around the world threatens our economy, our quality of life, and perhaps even the future of humankind. This situation is of great concern not only to the SoL community, but to all of us who at one time or another have been subject to the frustrations of scheduling appointments and sitting in waiting rooms, misdiagnoses, or operating room errors that result in poor outcomes and lack of confidence in the medical systems with which we have entrusted our lives. Likewise, as global citizens we are affected by social trends that have led to spiraling rates of obesity, type 2 diabetes, and inner-city poverty and violence. The articles in this issue offer intimate stories of patient-doctor relationships, of navigating personal medical crises, and of grassroots efforts to improve the overall health of local communities. We believe that these personal stories are an appropriate starting point for conversations about ways to renew and revitalize this critical system.

The first article, “Understanding Your Medical Mind: Decision Making Through Patient-Doctor Dialogue,” is an interview with Dr. Pamela Hartzband and Dr. Jerome Groopman, both nationally recognized experts in their respective fields. Based on recent research, Doctors Hartzband and Groopman have concluded that patients make decisions concerning their medical treatment partially based on their individual mindsets – their mental models. Further, their research shows that patient-doctor dialogue is a determining factor in whether patients regret or are comfortable with the course of treatment they chose, irrespective of the outcome.

In “Seeing the System Inside-Out,” Dr. Hugo Sax, head of the infection control program at the University Hospital of Zurich, describes his unexpected and disconcerting experience as a patient undergoing surgery. He shares in detail the physical and psychological aspects of his treatment as well as the insights he gained into some of the systemic barriers to change in the complex and uncertain environment of a hospital.

The practical application of systems thinking continues in “I Have Never Been Here Before: The Nonlinear World of Cancer,” an intimate portrait of how a serious health crisis forced learning and leadership consultants Marilyn Herasymowycz and Henry Senko to surrender their fixed ideas of truth and accept that complexity requires us to rethink everything we thought we knew, including our definitions of success. They describe how by giving us a way to simultaneously observe and participate in a system, systems thinking can provide us with a sense of calmness and control in the most challenging circumstances.

The final feature, “Change on the Scale of the Whole: Health, Peace, and Prosperity for All,” describes one city’s efforts to answer the question, “How do we make an unhealthy neighborhood healthy?” In this piece by Dr. Victor Garcia, a pediatric surgeon at Cincinnati Ohio’s Children’s Hospital Medical Center, we learn about a bold grassroots effort to interrupt a debilitating cycle in which social inequities feed an epidemic of violence and poor health. Through what Garcia calls a “brilliant accident,” he was introduced to systems thinking and Appreciative Inquiry, which have become the basis for an ongoing initiative to bring about large-scale change in Cincinnati’s “inner core.”

The current state of overall health and the effectiveness and cost of our healthcare systems concern us all. The articles in this issue highlight that the future of health and healthcare may be more promising when grounded in a personalized, systems-oriented, community-based approach focused as much on maintaining health as on restoring it.

Frank Schneider, Publisher
Understanding Your Medical Mind: Decision Making Through Patient-Doctor Dialogue

*Pamela Hartzband and Jerome Groopman, with Deborah Wallace*

The push over the last decade to standardize medical care has resulted in an increased use of metrics and regulatory guidelines – but not necessarily an improvement in patient satisfaction or overall health. In this interview, Dr. Pamela Hartzband and Dr. Jerome Groopman look at how current trends in healthcare tend to depersonalize care and reduce the time physicians have to talk with patients about their health. With little time for real dialogue, doctors often anchor their diagnoses on probabilities and initial impressions, while patients can feel “unseen” and even railroaded into making decisions. Pamela and Jerome propose a three-part decision-making framework that helps patients make difficult choices. This approach also supports patients and doctors in weighing the risks and benefits of treatment options together – an example of true patient-centered care.

Seeing the System Inside-Out

*Hugo Sax*

When Dr. Hugo Sax, a physician and the head of infection control for a hospital in Switzerland, entered the hospital as a patient, he had the rare opportunity to see a healthcare system from the other side. His experience brought into sharp relief the communication gaps and barriers to change that exist in most medical settings despite the best intentions of the staff. Equally surprising to Hugo was the ease with which he found himself falling into a dependent role, reluctant to question those responsible for his medical care or point out lapses in protocol that he witnessed. While his surgery was successful, Dr. Sax came away with more questions than answers about the ability of healthcare professionals and patients to navigate the complexities of caring for the individual as a whole.

I Have Never Been Here Before: The Nonlinear World of Cancer

*Marilyn Herasymowych and Henry Senko*

When consultant Marilyn Herasymowych was diagnosed with non-Hodgkin’s lymphoma, her world was turned upside down. But rather than become paralyzed by fear, she and her husband Henry Senko did what they had always done when facing uncertainty – they applied the learning system they previously designed to help people in organizations think and act more effectively in highly complex situations. Marilyn and Henry share their reflections on how Marilyn’s cancer diagnosis and treatment forced them to surrender their fixed ideas of truth and accept that complexity requires us to rethink everything we thought we knew, including our definitions of success. They find that by giving us a way to simultaneously observe and participate in a system, systems thinking can provide us with a sense of calmness and control in the most challenging circumstances.

Change on the Scale of the Whole: Creating Health, Peace, and Prosperity for All

*Victor Garcia*

As a pediatric surgeon at one of the world’s most prestigious children’s hospitals, Dr. Victor Garcia was deeply disturbed by the growing number of children being admitted with intentional gunshot wounds. Determined to find a fundamental solution to the cycle of poverty and violence that plagued the city’s “inner core,” Garcia turned to Peter Senge’s work on systems thinking and David Cooperrider’s Appreciative Inquiry methodology for guidance in creating sustained “change on the scale of the whole.” Victor gives an overview of the worsening trends buffeting many of our inner cities and the steps a group in Cincinnati has taken to begin to turn the tide in a more positive direction. By building on the community’s inner strengths, this group seeks to promote true health and prosperity for all of the city’s residents and stakeholders.
Deborah Wallace: We are always hearing ads and reading brochures assuring us that a particular hospital or clinic focuses on patient-centered care. It’s their guiding principle, and it’s what they strive for. How do you define patient-centered care and why do you think it’s attracting so much attention now?

Pamela Hartzband: We think of patient-centered care as care that is customized to the particular individual. Not only is it specific to your particular medical conditions and your age and gender and so on, but also to your preferences – how you weigh risk and benefit.

Jerome Groopman: There has been a tremendous movement to standardize medical care over the last decade. This has resulted in mandatory guidelines that are based on averages of populations and really don’t center on the individual patient. Many people have multiple medical conditions that are not encompassed or covered by these standardized guidelines. Nonetheless, these guidelines are mandated. There is a history over the last decade of repeated failure and, indeed, harm to patients caused by such mandates.

The other issue is that medicine is becoming industrialized. We are constantly hearing metaphors about healthcare as a factory, that your doctor’s office and...
hospital are assembly lines. We are called “providers” who basically give prefabricated treatment. And this is supposedly all in service of saving money. But it depersonalizes care.

**Wallace:** How much progress do you think we’ve made toward really delivering patient-centered care as opposed to delivering medicine in what Jerry termed a more industrialized fashion?

**Groopman:** Well, you know, it’s ironic because we were trained 35 to 40 years ago to focus on the individual patient. Now it’s been renamed “patient-centered care.” Back then, we certainly discussed

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One problem is that there are many different guidelines and different expert opinions. For example, the guidelines regarding the treatment of high blood pressure are different in the United States than they are in Europe. But even more importantly, people are different. They weigh risk and benefit differently. In medicine, we are always balancing potential risks with potential benefits, and the ways people do that can be quite different. After all, it is the patient, the individual, who ultimately accepts the risk of harm associated with taking a medication or having a procedure or test, so clearly patients should have a say in what they choose to do or not do.

**Groopman:** As Pam said, our concern is not the domain of medicine where everyone agrees. No one wants to have an unnecessary infection; no one wants to have a scissor left in his or her belly after an operation. But once you move out of that domain, it’s a gray zone. It is not black or white. If you are 75 years old and your blood pressure is moderately elevated and you take a blood pressure medication that can either dehydrate you or make you dizzy, the benefit to you can be very small in terms of preventing a stroke or heart attack compared to the fact that it will make you feel miserable and you could fall and break your hip.

**Wallace:** How much progress do you think we’ve made toward really delivering patient-centered care as opposed to delivering medicine in what Jerry termed a more industrialized fashion?

**Groopman:** Well, you know, it’s ironic because we were trained 35 to 40 years ago to focus on the individual patient. Now it’s been renamed “patient-centered care.” Back then, we certainly discussed evidence, clinical trials, clinical experience, and so on and how they applied or did not apply to individuals. A recent piece in the *New England Journal of Medicine* noted that not a single quality measure mandated by Medicare from the Center for Medicare and Medicaid Services is responsive to patient preferences. A lot of lip service is now being given to patient-centered care, but in terms of the track record over the last decade, the reality is that the shift has been to standardization. Quality measures do not address patient preferences.

**Hartzband:** There are metrics and guidelines that are specifically targeted to what happens in the hospital. Some of these are extremely helpful, like guidelines regarding ways to avoid infections in the hospital and prevent errors in the operating room. Both are very important, and standardizing the approach to procedures has been successful in these areas. But guidelines are less helpful when we are talking about decisions with individual patients about their treatment.

Our concern is that the really important work that’s done in the domain of safety is now being extended to other domains where choices are not black and white. And as Pam said, experts disagree. They are looking at the same information and data but they disagree because they value it differently. So why should their values be superimposed on a patient?

**Wallace:** Can you give us an overview of the process that you use when you are working with patients who have to make difficult decisions?

**Hartzband:** Although patients are obviously individual in how they make their decisions, we found in our field research that there are common threads. Some people are what we call *maximalists* – when it comes to medical treatment, they want

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**A lot of lip service is now being given to patient-centered care, but in terms of the track record over the last decade, the reality is that the shift has been to standardization.**
everything and more. At the other end of the spectrum are the *minimalists* – to them, less is more. We found that some people have a *technology orientation*. They want the latest, greatest high-tech breakthrough. Others have a *naturalism orientation*. They prefer natural healing, such as supplements, herbal treatments, or acupuncture. Finally, some people are what we term *believers*. Believers are certain that there is a good solution to their problem, and once they find it, they go for it. At the other end of that spectrum are the *doubters* who worry that the treatment will be worse than the disease.

People develop these mindsets in part because of their own prior medical experiences, but mindsets are also shaped by their family’s health and the medical experiences – both good and bad – of family and friends. Your medical mindset is your starting point. It is your initial approach to a medical problem. But you can change. You want to consider whether your initial approach is the right one for the particular problem you are facing.

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**Your medical mindset is your starting point. It is your initial approach to a medical problem.**

The next step is to consider numbers and statistics. You need to understand if the numbers apply to you as an individual or not. And you need to be aware of how numbers are presented. Are they presented or framed in a positive way or a negative way? This can influence how you react to those numbers.

Finally, you need to consider stories. We are all very much affected by stories. If your Aunt Sue took a medication and had a side effect, you are not going to want that medication. But it is not
only the stories from your family and friends. It can be a story in the newspaper or on the Internet. Psychologists call the effect of stories “availability,” because the powerful story stays in your mind and is readily available. These stories cause you to overestimate the likelihood or probability of that same thing happening to you.

The stepwise process is to first start with your medical mind. Second, look at the data, how it applies or does not apply. And third, see how stories sway you.

**Groopman:** So the stepwise process, as Pam said, is to first start with your mindset, your medical mind. Second, look at the data, the information, how it applies or does not apply. And third, see how stories sway you one way or another. Most scientists and decision analysts dismiss stories. They say, “Oh, they are just anecdotes.” But Daniel Gilbert at Harvard and other psychologists see stories differently. Gilbert published a terrific paper in *Science* called “The Surprising Power of Neighborly Advice.” In that paper, he says that it’s impossible to try to forecast or imagine what a certain experience might mean for you as an individual. Gilbert found that talking to people, particularly people who are similar to you in background and sensibility who have already experienced the same situation that you will be experiencing, can help give you a concrete, palpable sense of what your life may be like in the future. This conversation can help inform your decision.

For example, we found this was particularly helpful for several men struggling with their choices after PSA test results showed up positive for prostate cancer. Should they just be watched, so-called “active surveillance”? Should they have surgery? Should they have radiation? This is a gray zone. Talking to other men who made different choices greatly helped them come to a decision.

**Wallace:** It would be interesting to hear about each of your medical mindsets, because I know they are not the same.

**Groopman:** I’ll start. I was raised in a traditional, Eastern European Jewish family where the doctor was on a pedestal. Everything that the doctor said you did – and you did it to the maximum. I was raised with a maximalist mindset. I also was raised with a believer mindset that everything had a solution. The solution came from the doctor, and it meant better health.

I also was raised with a very strong technology orientation. In our family, the pioneers in polio – like Jonas Salk and Albert Sabin – were ranked as high as Winston Churchill and FDR in World War II. Finally, anything that was natural, as Pam talked
about, the naturalism orientation, was seen as being an ignorant throwback to the European village life and discounted. This informed my choice to become a hematologist and an oncologist, particularly at a time when bone marrow transplant, which is the most extreme and intensive kind of treatment, was being developed. It would save lives of people with leukemia and lymphoma who otherwise would have died.

Hartzband: I had a different kind of upbringing. When I was born, the doctor explained to my parents that the new, scientific way to feed babies was to feed them every four hours by the clock. I was the first baby in the family, and my dad was an engineer and very enthusiastic about applying scientific principles to child rearing. He made a chart for my mother so she could check off the box after she fed me every four hours. Dad went off to work, and my mother had a very stressful day with a lot of screaming from me, the baby. She finally took matters into her own hands and decided to feed me when she thought I was hungry. When my dad came home he was appalled. He asked my mother, “How could you not follow the advice of the doctor, the experts?” And like a true doubter, her response was, “Well, doctors don’t know everything.” The doubter mentality was how I was brought up.

My parents were ahead of their time with respect to a healthy lifestyle. We had to eat whole-wheat bread, which was not a particularly tasty item in the 1950s, and we were not allowed to have soda. My dad used to get my sisters and me up early in the morning to do the Royal Canadian Air Force exercises with him. By virtue of their lifestyle and/or their genetics, my parents have had long and healthy lives without much medical intervention. My dad is 88 this year and still goes out and runs, works out in the gym every day, and then works on his computer. My mom plays golf and is active. All that contributed to my minimalist, doubter point of view.

Wallace: In listening to you, I’m wondering whether you see these frameworks as mutually exclusive.

Hartzband: As a minimalist and a doubter, my first reaction to a screening test like a colonoscopy is that I don’t want to have it. I think about all the potential problems that can happen during this kind of procedure, the risks, the complications. Of course, that doesn’t mean I won’t do it. But I have doubts, and this influences how I go about making my decisions. I’m not willing to accept that everyone must have this or that test or procedure. I think to myself, is this really right for me? I’m not sure. I have to think about it. That is my process.

Groopman: I’m sort of a “maximalist in recovery,” because as I said, my starting point was very strong that way. I should also add that my father had a massive heart attack and died in his early fifties and didn’t get intensive cardiac intervention in the small community hospital in Queens, New York. That reinforced my maximalist mindset. I applied that mindset to back pain that didn’t have a clear cause; it wasn’t a huge ruptured disk. I went ahead with back surgery, and it was a catastrophe.

It’s important to realize that your doctor also has these mindsets. So not only do you need to consider your mindset, but also your doctor’s mindset.

What I learned from that was to temper my inclinations. As we said, in the three-step process, your mindset is your starting point. It’s important to first recognize how you generally approach problems, then to move along the spectrum one way or another, given the situation. I still believe that for many people with acute leukemia, bone marrow transplant is curative. For most people, the alternative is death. Some people say, “I don’t want to take the risk and end up with potential complications,” and they make the choice not to be transplanted. Sometimes they are at the end of the bell-shaped curve and may go for months to years without the typical downhill course. They are staying with their initial mindset, but a lot of doubters
and minimalists realize that they need to shift their mindset.

Hartzband: It’s important to realize that your doctor also has these mindsets. So not only do you need to consider your mindset, but also your doctor’s mindset. Often we hear patients say, “I went to a specialist and he told me one thing. And then I went to another specialist and he told me something completely different. Why?” We believe this happens because of different mindsets. The specialists have access to the same data, they are reading the same studies, but they value them differently.

The mantra now in healthcare is about systems solutions and efficiency.

Groopman: Look at the controversy over mammograms. The government panel, the United States Preventative Services Task Force, recommended against routine mammograms for women between the ages of 40 and 49. Other expert groups like the American Society of Clinical Oncology, composed of medical oncologists, disagreed. It’s not because they are corrupt or looking to make a buck – which is sometimes the way they are portrayed – it is because they weigh risk and benefit differently.

Hartzband: I’ll give you an example from my own practice as an endocrinologist. I often see patients with thyroid nodules, lumps in the thyroid gland. Most of these are benign, but some of them are malignant. We generally evaluate these nodules by doing a needle biopsy, but sometimes, even with the best technique and repeated needle aspirations, you can’t get enough cells. Then you need to decide if you are going to just live with this nodule or if you are going to take it out surgically. The risk of malignancy in a situation like this is low, less than 10 percent.

I recently had a patient in just this situation, a woman who had multiple biopsies without enough cells to make a diagnosis, and she asked me, “What would you do?” Now that’s an interesting question. Doctors are asked it all the time: “What would you do for yourself or your mother or your sister?” My answer was, “Well, given your particular situation and the way your nodule looks on ultrasound, I would watch and wait. But my husband (Jerry) would have had surgery yesterday.” So that’s the difference between the maximalist and minimalist mindset.

Wallace: Jerry, in an interview in US News & World Report, you made a powerful statement about the importance of listening and language. You said, “The errors that we make in our thinking often come about because we cut off dialogue. Most physicians interrupt a patient 18 seconds after they start talking.” This was so interesting to me, the whole notion of the fundamental importance of language and listening and the consequences when it is missing from patient-doctor conversations where decision making is so critical. How did you arrive at this as a fundamental principle that you rely on so heavily?

Groopman: Let me make a distinction between two things. The first is making the correct diagnosis, and the second, which is what we discuss in our book Your Medical Mind, involves treatment. Both are relevant to dialogue.

The finding of interruptions every 18 seconds was shocking to me, too. We found this number in studies: from the University of Rochester; from Judith Hall, a psychologist at Northeastern University; and from Debra Roter, who is at Johns Hopkins. The mantra now in healthcare is about systems solutions and efficiency. In a 12- to 15-minute visit, the doctor, nurse practitioner, and physician assistant are required to fulfill certain quality measures by checking items off a list or they don’t get paid. They have to ask patients if they wear bike helmets, if they wear seat belts, and if they smoke, even when they know that that person doesn’t smoke. Every single visit, you have to check these things off, and you have very little time left for real dialogue.
In England, for example, where these kinds of quality metrics have been mandated as they are now in the United States, studies have found that often patients go to the doctor and their primary problem, why they scheduled the visit, was never really addressed because time was consumed with all of these efficiency and quality measures.

With regard to diagnosis, the “anchoring error,” where a doctor will immediately grab one of the first things a patient says and anchor onto it, is a classic cognitive error defined by Kahneman and Tversky. When people stop on the first data point and then move in a linear way without allowing other information to be adequately considered, the result is often misdiagnosis.

In terms of what Pam and I were talking about earlier, patients weighing risk and benefit, studies from the University of Michigan show that in common medical problems, such as hypertension treatment or high cholesterol treatment, or choices about orthopedic procedures, in a half to two-thirds of cases, doctors do not explore with patients their own preferences and how they weigh risk and benefit. The result is that the doctor puts out his or her own preference and recommendation, and the dialogue becomes centered around what the doctor thinks about risk and benefit.

So we could not agree more that open dialogue and time to think, so-called “cognitive work” with a patient, is essential, and that the system is moving to snuff it out. We are returning to a paternalistic system where little time is given for dialogue. Rather, we have top-down management, where “we know” what is right for everyone. He said, “When I am walking on the golf course, all of a sudden, I lose my stamina, right here in my calf.” So what he was talking about was a classic symptom of intermittent claudication, where the blood supply to the leg is partially obstructed. When you exercise, there is an increase in the demand for blood, so you get fatigue and cramping in the leg. That’s what he meant by stamina. This diagnosis was confirmed through additional testing, and he was treated in the appropriate fashion. That big expensive work-up he had gone through before was unnecessary, and it happened because there had not been enough exploration into the language.

We interviewed a doctor who told us the story of a patient who complained that he was losing his stamina. His doctors put him through a big work-up, first a cardiac work-up and then a pulmonary work-up, both negative, and nobody could figure out why he was losing his stamina. Finally, one of his doctors asked him to describe exactly what he meant by “losing his stamina.”

We are returning to a paternalistic system where little time is given for dialogue. Rather, we have top-down management, where “we know” what is right for everyone.
Wallace: So it took that whole series of tests, all that money, all that time before somebody asked the right question.

Hartzband: Yes, exactly.

What people don’t realize with top-down management is that by snuffing out open-ended discussion and having everything in templates, doctors don’t think or talk in real dialogue. What they are doing is fitting the patient into the box.

Groopman: What people don’t realize with top-down management is that by snuffing out open-ended discussion and having everything in templates to fit into an electronic record, doctors don’t think or talk in real dialogue. What they are doing is fitting the patient into the box. There are unintended consequences, and many of these organizational reform measures actually work against patient-centered care.

Wallace: Interesting. So we’re moving toward Taylorism?

Groopman: That is it. It is Taylorism. I read a piece about the history of Frederick Taylor. It showed that most of the research results that he proposed turned out to be illusory. He found one big, strapping guy who could shovel coal or whatever it was ferociously.

Hartzband: But the guy couldn’t move the next day. He couldn’t do it two days in a row. Never-theless, that became the target work level for everyone.

Groopman: People who rely heavily on quality measures believe in Taylorism. The other thing is they believe we can measure everything important. And we can’t. There are dimensions in medicine that cannot be reduced to simple numbers, but they don’t see it that way. Their assumption is if you can’t measure something, you can’t manage it. So they want to manage everything, and they ignore the things they can’t measure.

Pam and I have a piece in The New England Journal of Medicine on this subject called, “There is More to Life than Death.” The bottom line is that experts ignore vital dimensions and vital issues that can’t be measured but that patients find important.

Wallace: When your patients experience poor outcomes, what is that conversation like? How does that shift the relationship with the patient and make it more difficult for both parties?

Hartzband: In our book, we tell the story of two patients who had elective orthopedic surgery for chronic pain. In both cases, the surgery did not resolve the problem. Both patients still had pain after the surgery. Both of them were disappointed, but one had regret, a heavy burden to carry, while the other did not. We found that the process of how the two patients made their decisions made a significant difference in how satisfied they felt.

The first patient was a man who had knee pain due to degenerative changes in his joint. Before surgery, he considered his mindset. He reviewed the numbers. He felt that he made the best decision he could at the time. Of course, as with all things in medicine, there is no guarantee that you are going to have a good outcome. You acknowledge this when you sign a consent form for surgery. He was able to accept the outcome and move past it.

The second patient was a woman who had foot surgery, also for degenerative changes. She felt that she had been pushed into doing something that didn’t fit with her mindset, and she was filled with regret that she made the choice that she did.

From the doctor’s perspective, understanding what the patient wants and why he or she wants it, and being sure that everyone agrees that this is right thing for this individual can help ameliorate
disappointment and prevent regret. Obviously, no one wants to have a bad result, but even with the best care, it can happen. Ideally, you and your physician face the bad outcome together rather than becoming adversaries.

**Groopman:** Your doctor is not a rubber stamp. A patient may come with a certain mindset, and often it’s good to challenge that. The process involves your mindset and the numbers and the stories. What shared decision making really means and what patient-centered care really means, to bring the discussion back to the first issue, is that there is a give and take and a consideration of the opposite point of view.

We are dedicated to preventing preventable errors and ensuring safety, but in much of medicine, you can do everything right in a procedure or you can give someone a correct medication, and a complication still occurs. And yet, as Pam emphasized, if you went through the kind of process that we propose, we believe that you can feel you did everything you could. That’s a very different feeling, for example, than feeling you were railroaded into something or as in my own case with my back surgery where with my sort of unbridled maximalism, I didn’t get strong pushback, which might have helped me. This is the art of decision making.

**Wallace:** What has to happen in the healthcare system or with individual patients and physicians

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It’s ironic that all of these people who come out of organizational thinking are now promoting efficiency in healthcare delivery, as if it’s like producing cars on an assembly line. That’s not what medicine is.
so that the greatest good is served and there is mutual benefit to all the stakeholders?

Hartzband: Of course, we think that everyone is entitled to good healthcare. What concerns us is that some of the most important dimensions of medicine are being lost in the push to cut costs. In particular, time is being devalued. The time that patients spend talking to their doctors is being limited in the name of efficiency, but this time is needed for accurate diagnoses and patient-centered decision making about tests and treatments.

What shared decision making really means and patient-centered care really means is that there is a give and take and a consideration of the opposite point of view.

We object to the new language of medicine where the doctor is a “provider” of standardized care and the patient is a “consumer.” This does a disservice to both doctor and patient. We think it’s a problem to equate standardization with improved quality. They are not the same. Improving quality will not always cut costs. We never hear about cutting costs without also hearing that this will improve quality. The mantra is that we are going to improve quality and cut costs, but a number of recent studies about congestive heart failure, for example, indicate that spending more results in higher-quality care.

There is waste and fraud in our medical system, and we need to work on eliminating it. While attempting to do so, we also need to preserve the core of what good medicine really is.

Groopman: We’re not ignorant of or ignoring the cost problem. Theodore Marmor, who is a professor of policy at Yale, and Jonathan Oberlander, who is at the University of North Carolina, have written pieces in the New England Journal of Medicine and other publications that say it’s a mistake to equate cost with quality of care. Look at countries like Germany, where there is a private not a socialized system like England. The way Germany controls costs is by very strict regulation of the insurance industry and their profit margins, and by having uniform and transparent pricing. Germans do not micromanage the care of individual patients. They don’t have the Taylorist approach of standardizing everything and seeing people as cars coming off an assembly line.

Insurance companies compete for customers in Germany based on perks and other services they offer, but that’s not what’s going on here in the U.S. You have two extremes. You have top-down management from the government, which is the Affordable Care Act, then you have top-down management from insurance companies, whose primary aim is profit. The idea that a single government panel is like the Vatican or the Sanhedrin – infallible, with divine wisdom that can standardize care for everyone all the time – is just an illusion.

If the safety issues are all addressed, large sums of money and lives will be saved. But there is no evidence from all these evidence-based policy people that strict standardization of other domains of care either saves money or helps people. In fact, it doesn’t.

We believe in universal coverage. There should be no discrimination on preexisting conditions, and we believe there should be very strict measures to protect patients with regard to safety, preventable errors, and emergency protocols. But we think it’s a big mistake to standardize everything. What’s driving it also, frankly, is enormous profits that are being made by insurance companies that now assert that they are the ones who can tell you which doctor to pick, which procedure to have, as though they are your advocate – and in truth they are not.

There are also experts jumping in and making fortunes by generating metric after metric after
Ideally, you and your physician face the bad outcome together rather than becoming adversaries.

metric. It’s a self-sustaining bureaucracy. Because if you said, let’s just focus and take care of catheter infections or operating room errors and things like that, the consultants wouldn’t have much work to do.

Hartzband: We are doctors but also sometimes we are patients. And when we are patients, we want our doctors to be thinking of us as individuals – to do what is best for us individuals.

Groopman: You often hear that you have to be “population-centered.” Well, there is no “population”; no average person exists. It’s a statistical artifact, and to ignore the gray zone and the tradeoffs that every patient makes in coming to a decision is really a disservice to patients and to the profession.

ENDNOTES


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The Story

For years, I had a tumor at the angle of the right side of my jaw, about the size of an olive pit or even smaller. It always stayed the same size, too small and stable to be worrisome. But recently it had grown, or so it seemed. When things change slowly they are difficult to judge. It didn’t hurt, but I was sure I had not seen it in the mirror like this before. No one else seemed to notice.

I had just changed my workplace and had to go to the staff doctor’s office for a tuberculosis skin test. A nurse greeted me and did the test. I told her about the tumor and that I was not sure what it meant. She suggested I talk to the physician about it. The physician thought I should have the tumor removed for histological examination. It seemed simple. We agreed that I should consult with an internist, which meant I was going to be seen by the chief of internal medicine at the same hospital where I worked.

The appointment was two weeks from then. After a few days, I got really worried about having to disclose all of my medical history to a colleague with whom I would probably have to wrangle over some tough political issues in the future. More days went by. Finally, I canceled the appointment and rang my internist in private practice in another town. Physicians are reluctant to have physicians as patients. My internist is a really good doctor with a practical approach to problems. She relies on a basic inventory of readily citable causes for specific symptoms based on the principle of “What is frequent is frequent.” We don’t generally work this way at the hospital, where a patient’s true diagnosis is usually buried somewhere among a long list of alternative diagnoses, each of which is associated with only a very low probability of actually being the right one.

I sat in the waiting room for some time. After examining me, my empathetic doctor suggested that I see an ear-nose-throat specialist for my parotid gland problem. He was young, she said, but excellent. He performed surgery at a public hospital, which to my internist was proof of his high level of skills. I was glad she pointed me in the right direction. The illusion that the quality of healthcare is consistent from

Seeing the System Inside-Out

HUGO SAX

When Dr. Hugo Sax, a physician and the head of infection control for a hospital in Switzerland, entered the hospital as a patient, he had the rare opportunity to see a healthcare system from the other side. His experience brought into sharp relief the communication gaps and barriers to change that exist in most medical settings despite the best intentions of the staff. Equally surprising to Hugo was the ease with which he found himself falling into a dependent role, reluctant to question those responsible for his medical care or point out lapses in protocol that he witnessed. While his surgery was successful, Dr. Sax came away with more questions than answers about the ability of healthcare professionals and patients to navigate the complexities of caring for the individual as a whole.
hospital to hospital seems to be a mental model that I’m still hesitant to challenge, even if I should know better.

The surgeon focused intently on my problem and always looked me straight in the eye. He smiled but never laughed. I had to sit on an examination chair a bit higher up than his. After examining me and listening to my story about the tumor getting bigger over the last few months, the surgeon readily offered a presumptive diagnosis.

The surgeon donned gloves to perform a needle biopsy, but I noticed that he didn’t use an alcohol-based hand sanitizer to first clean his hands. I currently head the Infection Control Program at the University Hospital of Zurich and serve on the World Health Organization’s First Global Patient Safety Challenge. We had just issued guidelines for hand hygiene procedures in an ambulatory setting.¹

What did I think of an excellent surgeon who was not following the rules? To tell the truth, although he did not follow the guidelines, I did not really worry about getting an infection.

The excellent young surgeon found another tumor in my thyroid and verified by ultrasound that it was a cyst. He suggested doing a needle biopsy to exclude malignancy there, too. Age must have added some equanimity to my emotional repertoire, since I did not faint or really panic. The surgeon told me that if the parotid tumor was what he thought, I would need surgery in the next six months. Otherwise, it would grow and become malignant at some time, making surgery more difficult. I went home, looked through my planner,

What did I think of an excellent surgeon who was not following the rules? To tell the truth, although he did not follow the guidelines, I did not really worry about getting an infection.
and decided to cancel a trip to the U.S. I scheduled the surgery for two weeks from that day.

Now I went back to my internist where I had a physical and lab tests done for the surgery. Simple medicine. Then I had to see the anesthesiologist in the hospital I was going to be operated in. She gave me choices I did not want, more choices probably than she would have given to a non-physician. I worked as an anesthesiologist at the beginning of my career, and some of the drugs she offered sounded familiar, others not. When it comes to your own health, there is something about choice that is uncomfortable. Too often, too much data is missing.

When it comes to your own health, there is something about choices that is uncomfortable.

Finally, back at the surgeon’s office to sign the informed consent form, what was in my mind a simple inch-long cut became a three-hour high-precision surgery. Three surgeons would attempt to avoid cutting the motor nerves that run through the parotid gland. If they happened to sever them, one side of my face would permanently droop, and eating would be difficult. My surgeon also announced that he would have to cut some sensory nerves, and my right ear would become numb in most parts. Other nerves that originally told the parotid to produce saliva would ultimately find their way to glands in the skin and produce sweat whenever I thought of or ate delicious food. He warned me that the remaining parotid tissue would still produce saliva and that for a short time after the surgery, drool might run down my face whenever I ate.

By then I had learned that the tumor was not malignant. But these potential side effects were unexpected and impressive. My meeting with the surgeon was on a Wednesday. The surgery was scheduled for the following Monday. On Thursday, my throat was sore, and by Friday, I was coughing badly. My body seemed to be trying to avoid the inevitable. On Sunday, my symptoms were worse, and I called the anesthesiologist to discuss the options. He made the decision to proceed with the surgery on schedule.

I was still not sure this was the right decision when I got to the hospital the next morning. I had no fever but a slight numbness to my skin, and a fog surrounding my head made everything seem a bit unreal. Everyone was exceptionally nice. Soon, what started out feeling like a trip to a hotel room ended up as everyday medical procedure, a sharp contrast to the idea of being deprived of the inner connection to a part of my body (my ear). Scheduled aggression.

Being in a cotton cloud somehow helped. I changed into the hospital gown, was pushed through the corridors on a gurney, and then had to shift to the hard operating table, the warm drapes contrasting sharply with the cold air and stainless steel surfaces in the anesthesia induction room. The anesthesiologist had a beard and a friendly face. I watched my heartbeat on the monitor, spotted some premature beats, felt the medication run up the vein in my left arm, and fell into an intimate nothingness.

I woke up in the intensive care unit with lots of commotion flying in from far away. I was in an exceptionally bright mood and immediately started to talk with an intern about her career prospects, purposely using open questions. Then I began to monitor hand hygiene activity. Everyone seemed to walk up to me without cleaning his or her hands. Clearly, I felt no risk of getting an infection; it was about the protocol. I forced myself to say something, but doing so was not easy. Here I was, having just survived a visit to the other side and back, dependent on the staff to know the routine, the medication, my case, and each other. Why should I dare to be critical about a protocol item? The system might fall out of its routine.

I remembered the findings of our focus group study, where participating nurses made sugges-
tions on how to solve the hygiene problem. In the interview transcripts, we saw an array of options ranging from boldly confronting non-compliers on one end to placing hand-sanitizer dispensers in front of patients’ beds on the other. Flooded by opioids, I was in a daring mood but still chose a soft approach. I asked the next nurse who came into my room whether the hand-rub dispenser was close enough to my bed for staff to think of hand hygiene when approaching me. We then got into a discussion about the importance of hand hygiene while caring for patients, she being squarely in favor.

These were beaten paths, somehow disjointed from current reality. The anesthesiologist came by

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**Efforts to Improve Patient Safety**

In October 2004, the World Health Organization (WHO) launched a patient safety program in response to a World Health Assembly Resolution (2002) urging WHO and member states to pay the closest possible attention to the topic of patient safety. The program, WHO Patient Safety, aims to coordinate, disseminate, and accelerate improvements in patient safety worldwide. It provides a vehicle for international collaboration and action among WHO member states, WHO’s secretariat, technical experts, and consumers, as well as professionals and industry groups.

In 2005, WHO Patient Safety initiated its first patient safety challenge under the slogan “Clean Care Is Safer Care,” led by Professor Didier Pittet and Dr. Benedetta Allegranzi. Subsequently, many more programs were developed to help countries, regions, and healthcare institutions tackle the issue of patient safety around the world.

As part of “Clean Care Is Safer Care,” an international panel of experts developed the WHO Guidelines on Hand Hygiene in Health Care as well as a set of complementary implementation tools for changing the behavior of healthcare workers. The core concept of “My Five Moments for Hand Hygiene” is based on breakthrough research conducted during the 1990s at the University of Geneva hospitals and later fully developed based on human factors principles during the Swiss National Hand Hygiene Campaign in 2005.* “Five fingers, five life-saving moments, five strategies of action” is a simple, user-centered concept for understanding, training, monitoring, and reporting on hand hygiene in a wide range of healthcare settings in the fight for infection-free hospitals.

The number “five” is also reflected in the designation of Global Hand Hygiene Day on May 5 each year. In 2012, more than 15,000 healthcare facilities in 156 countries worldwide, with approximately 10 million healthcare workers and 3.7 million patient beds, participated in this event. Since 2005, 48 countries have taken the additional action of initiating their own national hand hygiene campaigns.

Despite this progress, hand hygiene performance is still suboptimal, and too many otherwise avoidable infections still occur. Much remains to be understood and implemented regarding infectious risks and human behavior.

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with two younger physicians and asked how I was. They told me about some difficulties caused by my inclination to turn on my right side where the wound was, and about the need to treat a rash caused by the opioids with an antihistamine. But they didn’t use the hand sanitizer before shaking hands either. They walked on to the next patient without cleaning their hands. Why should I pose a risk to the next patient? How would she know that I didn’t?

Time went by, with me diving in and out of sleep. The cough came back as the opioids wore off, and I ran a high fever. Someone wanted my opinion on whether I thought I should have antibiotics. The anesthesiologist with the beard came for a visit, and he thought blood cultures were not necessary. Then a nurse came and did take blood cultures. She had to draw blood for lab tests as well and wanted to access the vein on my left arm where the IV was running. I mentioned the possibility of the tests being corrupted and suggested she use the arm without the IV. She obviously did not like my interference, argued that the IV liquid was running down a different vein than the one she would be using, but nevertheless went around the bed to draw blood from my right arm.

The nurse had perceived my remark as confrontational. Not good. And maybe she was right. Maybe it was a rule without much real value. What is the safety margin around this kind of procedure? Would an incorrect value in a blood test lead to a wrong decision that would end up harming me?

I was much less enthusiastic without opioids and back in my room. Many nurses came to see me. On the third morning, I realized that I had been served hot chocolate instead of coffee. I never drink hot chocolate for breakfast. I told the nurse, and he said no problem at all – he would see to it that I got coffee. The coffee never made it to me.

My surgeon came daily and made certain decisions that he said he would communicate to the nurses on his way out. The prescription he men-

My not-my-ear ear feels like my other ear from the inside but like someone else’s ear from the outside. I still wonder how it gets along being disconnected like this.
tioned didn’t materialize. On the third day, I was transformed back to a civilian in private clothes, sitting on the balcony to test my overall condition for half an hour. Then I left, dragging my wheeled carry-on bag over many curbs to the local suburban train station. My ear was covered and hurt only faintly. It still belonged to the hospital until I got home.

Reflections
This experience made me reflect on systems. I had the rare chance to see a system from the other side. It recently occurred to me that observing myself was probably the most valid research method I had ever used, breaking through a solid mental model on the value of more prescribed research methods. But there is a clear limit to that N=1 sample size. As a physician, I have certainly had a huge blind spot in terms of considering patients’ experiences. Here was an opportunity to see what happens to a patient by being the patient, which is radically different, a 180-degree role change.

What impressed me most was the normality of what was going on in the hospital, the ease with which everyone navigated the system and their roles in it, and the empathy and good intention with which everyone approached me as a patient. The nurse certainly took it to heart that I would not agree with her first choice of arm from which to draw blood, probably not because she felt “caught” but because she had been doing it that way for a long time to the best of her knowledge and with professional pride.

In my professional life, I work to help hospitals identify and avoid medical errors. Where are these kinds of errors hidden? When people are ferociously focused on the task at hand, errors may be latent and difficult for those involved to see. While writing about my hospital experience, I serendipitously read the work of Carol Moulton and colleagues. They suggest that true expertise is the ability to switch from routine task-execution mode to a more conscious reflection-in-action mode whenever the situation becomes non-routine. It is, they explain, the ability to “slow down when you should.” When freed from their reliance on learned routines, experts should then be able to invest their mental resources in approaching more complex aspects of their work with greater mindfulness.

During my three days in the hospital, I saw many, many small bits of information get lost, much guesswork around decisions, missing data that might inform those decisions, breaks in information chains, and information stored only in the memories of people who then left, with others coming in and starting off at zero. It seemed as though the stream of information was broken in pieces. These details mostly concerned trivial things, but aren’t big incidents the result of the unlucky lineup of small glitches? I noticed how important an increased flow of systems-level information could be.

True expertise is the ability to switch from routine task-execution mode to a more conscious reflection-in-action mode whenever the situation becomes non-routine.

I was equally impressed with how easily I gave up my usual role and became a patient to fit the system. It was as if the system had invaded me and the only chance I had to survive in this other reality was to blend into the general flow, to borrow from that normality. Maybe I felt that if I objected, I would make myself more vulnerable to fate.

My failure to react more strongly to each missed hand hygiene opportunity may have been rooted in my same reluctance to disturb a system running smoothly. But then, it may have been a bias toward optimism in the face of more severe and immediate threats such as the possibility of not waking up from anesthesia, my cough becoming bacterial pneumonia, or my tumor being cancer after all. The risk of being infected by an individual touch of unclean hands is indeed very, very small, with
the overall risk definitively lying in the many, many hands touching many, many patients every day in a hospital. This risk paradox is a huge motivational challenge. When I think back to my excellent surgeon and all the other kind, competent staff, a halo effect might be at work here: how can someone competent do something that would harm me?

Was I just lucky or is the system sufficiently redundant, equipped with the necessary safety margins?

Healthcare workers who participated in our focus groups on hand hygiene have told us that they switched roles in a snap when they became patients. I have now confirmed this trend. My experience reminded me of innovative research into the patient’s view of the system by Dr. Gretchen Berland. She gave patients video cameras to capture their lives in wheelchairs. An exceptionally rich picture resulted from their interactions with the healthcare system, something Dr. Berland felt would be healing for those on the other side to see.

To me, the question of how and where healthcare workers and patients can come to a meeting of minds remains open. I’m not just talking about physicians allowing patients to participate in the decision-making process, but also both parties sharing the experience of uncertainty. Today, patients are involved in therapeutic decisions. Doctors try to explain the data behind each choice. But since the outcome of each choice is mostly unpredictable, much determining data is missing, and the boundaries of intuition remain fuzzy even to the experts, making a choice as a patient really comes down to tempting fate, which is very scary.

The most constant element during my hospital stay was my surgeon’s daily visit. He looked at me with his straight gaze and focused on the healing of the surgical site. Was this approach his mind’s way of avoiding being trapped by complexity? He had told me there would be no infection and there wasn’t. And other bad things did not happen either. Was I just lucky or is the system sufficiently redundant, equipped with the necessary safety margins? Or did the “What is frequent is frequent” rule apply here as well?

ENDNOTES


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In “Seeing the System Inside-Out,” a medical procedure provides Dr. Sax with a new perspective on a healthcare system that he has been working to improve. His reflections on his experiences as a patient bring the human element to the surface in what is often an abstract analysis. As a physician who has also been a patient within an organization I was trying to improve, I recognize in Hugo’s story the familiar struggle in any kind of change work to see past our entrenched mental models in order to have a significant impact, in this case, to ensure the delivery of safe, high-quality healthcare.

Being able to touch, feel, and experience the system as a participant, and then to be able to reflect upon it as one of its designers, is an insightful gift that Dr. Sax offers through his story. A number of insights – lessons related to how we see systems and how we might more effectively work to change them – are worth mentioning here.

1. Fragmented Perceptions Present a Significant Barrier to Whole-System Improvement

It is no surprise that, in healthcare, disconnection among different functions and specialties often leads to negative outcomes, including harm to patients, inefficiencies, and high costs. Many of the lapses that Dr. Sax experienced during his treatment are fundamentally related to the fragmentation of a system intended to serve and heal individuals in their most vulnerable moments.

As a physician, I can’t help but wonder if some of this fragmented world view is tightly intertwined with our diagnostic approach. We have been trained to think in a manner that is deductive and reductionist in order to sift our way through a long list of potential diagnoses (this list is the so-called “differential diagnosis”). When something is “ruled out,” it’s removed from the list of possibilities and never considered again. Essential in providing clarity in our journey toward a diagnosis, this approach doesn’t always serve us well in understanding complex and highly interrelated systems, where effects can be separated significantly in time and space from an intervention. In my experience, this reductionist way of seeing the world isn’t unique to physicians, but has a tendency to migrate to other disciplines in the industry such as nursing and management.
It is this fragmentation that leads to unsatisfactory experiences for a patient, such as multiple referrals and hand-offs, information gaps, and unintended consequences. We see that from the time of Hugo’s diagnosis, many different providers are involved. The nurse, the chief of internal medicine, the personal physician, the anesthesiologist, and the ear-nose-throat specialist are all highly trained and do exceptional work in their respective areas. But who is responsible for the systems perspective? If the ear-nose-throat specialist makes a recommendation with an unintended consequence that occurs in an area outside of his specialty, how is he to know and how are others involved in the patient’s care to know?

We frequently find out about decisions by other medical professionals that affect our patients after the fact, when we may have missed the opportunity to foresee, prevent, or mitigate an unintended consequence. We assume that communication takes place to avoid these sorts of dilemmas, and indeed it often does through a letter or a quick phone call from one physician to another, but the quality of these communications (often asynchronous, linear, and unidirectional) is suboptimal for seeing the patient as an integrated person. The system is unable to view itself as a whole, something that often creates unsettling experiences for the individuals it is intended to heal.

This fragmentation also leads to challenges with the implementation and spread of best practices based on evidence (such as hand hygiene procedures). We hope educating and reminding health providers about these practices will be sufficient to change their behavior, but our experience does not bear this out. Even well-meaning, well-educated individuals may have difficulty adhering to a standard practice consistently because of unseen systemic barriers. Declarations alone simply don’t work. I have seen organizations in which purchasing policies have resulted in situations that actually discourage hand hygiene – dispensers that jam so that product can no longer be dispensed, products that lead to excessive drying and cracking of the skin, or dispensers installed in locations too distant from where the patient workflow takes place to be convenient. In these cases, the costs of an unnecessary infection far outweigh the costs of improving the flawed policy or faulty practice.

For a practice to be fully adopted, we must clearly understand how the system’s dynamics can either help or hinder its implementation. Common systems archetypes are everywhere in healthcare; the examples above are related to the “Fixes That Fail” archetype, but others are frequently at play in healthcare scenarios as well. By learning to identify these common patterns of behavior, we can design interventions that avoid their most damaging effects.

### 2. Systems Thinking Is Essential for Success in Health System Redesign

The good news is that many health systems are moving away from fragmentation and silos and toward greater levels of integration through team-based approaches to care. Common systems archetypes are everywhere in healthcare; the examples above are related to the “Fixes That Fail” archetype, but others are frequently at play in healthcare scenarios as well. By learning to identify these common patterns of behavior, we can design interventions that avoid their most damaging effects.
payments, accountable care organizations, and clinically integrated networks. In essence, all of these arrangements involve the creation of a shared economic interest around a common resource pool that must manage all parts of the system for its mutual benefit. As these models are created, it is increasingly common to see systems archetypes such as “Tragedy of the Commons,” “Accidental Adversaries,” and “Shifting the Burden” (or some variation of these basic archetypes) emerge as competitors find themselves having to collaborate in new ways. Among health system leaders, a better understanding of system dynamics and an awareness of common systems archetypes will improve the chances for success.

3. Emotions Have an Effect on Seeing Systems Whole

Why is it so difficult for leaders to see and understand systems? Too often, we have the best intentions as we attempt to understand the big picture, but we underestimate the effects that our emotions have on how we see (or do not see) what is actually happening. Strong emotions such as fear and anxiety can activate our fight-or-flight response and introduce a significant bias that colors our perceptions of the dynamics at play. This response, designed for survival and self-protection, causes us to focus on a subset of available data, from which we make rapid interpretations, akin to “climbing the Ladder of Inference.” At a time when we’re trying to understand the nuances of a complex challenge, our emotions can limit our perceptive capacity.

As a patient, Dr. Sax notices failures of individuals within the system to follow a well-proven hand-washing protocol designed to reduce avoidable infections for hospital patients. When patients or coworkers observe failures to follow the protocol, what hinders them from reminding the individual about the appropriate behavior? Physicians tend to have a worse track record in adhering to hand hygiene recommendations than other groups, yet patients and nurses seldom point out their lapses to them. Power dynamics and culture, anchored in long-standing mental models, may hinder people’s willingness to question those with more perceived authority.

Without the ability to question itself, though, the system is deprived of the feedback necessary to improve performance. And when we fail to see safety lapses as stemming from properties of the system, we tend to place the blame for less-than-ideal outcomes on individuals, further contributing to a reinforcing loop that diminishes curiosity and impedes learning. For this reason, if leaders in health system redesign are to increase their capacity to see, understand, and transform systems, they must manage fear and anxiety, while creating a place for mindfulness and curiosity.

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I Have Never Been Here Before: The Nonlinear World of Cancer

MARILYN HERASYMOWYCH AND HENRY SENKO

When consultant Marilyn Herasymowych was diagnosed with non-Hodgkin’s lymphoma, her world was turned upside down. But rather than become paralyzed by fear, she and her husband Henry Senko did what they had always done when facing uncertainty – they applied the learning system they previously designed to help people in organizations think and act more effectively in highly complex situations. Marilyn and Henry share their reflections on how Marilyn’s cancer diagnosis and treatment forced them to surrender their fixed ideas of truth and accept that complexity requires us to rethink everything we thought we knew, including our definitions of success. They find that by giving us a way to simultaneously observe and participate in a system, systems thinking can provide us with a sense of calmness and control in the most challenging circumstances.

Planning for Limits

MARILYN

At 1:00 pm, March 17, 2009, I was diagnosed with non-Hodgkin’s lymphoma. At 4:00 pm that afternoon, I was admitted into the hospital because I had a lot of trouble breathing. There I was, sitting on a bed in Emergency, Henry holding my hand, waiting to meet the oncologist. I remember feeling like a little girl going to her first day of school. It was surreal. I had a paradoxical feeling of both anxiety about the cancer diagnosis and curiosity about being admitted into a hospital. Henry was very calm, and I was a chatterbox, talking about what we had just heard and what this might mean. We had just sold our house and we needed to move, and here I was being admitted into the hospital in a city that was two and half hours away from where we lived. Henry smiled and said, “I guess we better start planning for limits.” We both laughed.

Henry and I had no idea how important “planning for limits” would become to helping us to deal with the most profound uncertainty of our lives – my cancer diagnosis. This would become even more critical as we went through cancer treatments, and dealt with the aftermath of vicious side effects and the agonizing change in our life that would become our new normal.

We had spent the last 20 years in MHA Institute creating a learning system to help people in organizations to think and act more effectively in highly uncertain situations. Part of this learning system, which is based on the classic systems archetypes, uses a language and patterns of behavior to describe what people are experiencing. Another part of the learning system provides pathways through the difficulties, in order to create new patterns of behavior that are beneficial to both people within organizations and
the organizational goals. This learning system works because it gives people a way of thinking about uncertainty that makes it easier to act, rather than to react to the difficulties that uncertainty unleashes.

When Henry said, “I guess we better start planning for limits,” he was using the language of this learning system we had created. We were dealing with a pattern of behavior called “Limits to Success,” and the pathway through “Limits to Success” is called “Plan for Limits.” When Henry referred to “planning for limits,” he refocused our thinking so that we could quickly identify our limits and start dealing with them effectively, thus reducing the anxiety that we felt about the uncertainty. Doing this helped us to feel more in control, and more able to take in information about what was happening and what choices we might have to make.

“Plan for Limits” provides a number of strategies to consider when dealing with “Limits to Success.” The one that was most relevant to us at this time was to identify current limits. While we waited in Emergency for the doctor to arrive, we started talking about our current limits and what we had to do to deal with them. The first limit that we faced was that I was in a hospital in Lethbridge, Canada, and we lived in Calgary, two and a half hours away. The second was to reschedule our work with clients, so that Henry could deal with emerging issues from this diagnosis and my stay in the hospital. The third was that we had just sold our house and we had less than 60 days to find a new place to live, then pack and move. We had to deal with the first two limits right away. The third limit would have to wait until tomorrow.

**HENRY**

We were introduced to the field of systems thinking many years ago when Marilyn read Peter Senge’s first book, *The Fifth Discipline.* At the time, she was working in curriculum development for a government agency. A few years later, we went into business for ourselves. We took courses from Innovation Associates in Canada to learn about systems thinking. We then had an opportunity to introduce the idea of systems thinking to a client. From that point forward, we continued to work with the ideas associated with the learning organization.

In February 1995, we met Peter Senge and Charlotte Roberts at a presentation in Edmonton. Marilyn asked for their signatures in her copy of *The Fifth Discipline Fieldbook.* She had used it so much in testing the activities with others that it was falling apart. I remember both Peter and Charlotte being surprised at the condition of the book.

The book was ragged because we used it in learning circles once a month. These learning circles were open to anyone. We started in our home and then moved to hotel meeting rooms owing to the number of people wanting to attend. We decided...

Henry and I had no idea how important “planning for limits” would become to helping us to deal with the most profound uncertainty of our lives – my cancer diagnosis.
to focus on the systems archetypes, or universal patterns that describe patterns of behavior in complex situations. At the time, researchers and practitioners at MIT’s Center for Organizational Learning had developed 10 archetypes that described negative or undesired patterns of behavior. For example, “Fixes that Fail” summarizes a pattern of behavior in which people react to a problem in real time without considering possible negative side effects. (See Table 1 on page 26.)

The definition of “Planning for Limits” is that you continuously identify, monitor, and plan for limits that may occur and/or are occurring in the system. These limits are constraints or pressure. For us, the immediate pressure was related to client work.

Over the longer run, the 20 classic and positive archetypes gave us a way to come up with what we thought of as a strategic plan and to evaluate and test different courses of action. Other people in a similar situation may find a different approach useful. The key is to find a way to sort through the reams of information and make meaning from it, to turn chaos into complexity. For us, the archetypes provided a shorthand language and set of storylines to guide our thought process and communication.

When we found ourselves in the emergency room faced with an uncertain, ambiguous situation, we turned to our learning system for guidance.

People in our learning circles found these archetypes very useful in understanding the complexity of their situations and were able to take more effective actions as a result. They noticed that the archetypes made it easy to have a respectful and honest dialogue about what was really going on in their situations. At the same time, the test groups also wanted a way to understand what was working in their situations. As a result, Marilyn and I developed 10 complementary positive archetypes that describe positive or desired patterns of behavior. (See Table 2 on page 27.)

When we found ourselves in the emergency room faced with an uncertain, ambiguous situation, we turned to our learning system for guidance. This approach gave us a language for sorting through the information we had and planning for the near future. Even though our emotions were running high, framing the information using the positive and classic systems archetypes helped to put us in a logical mindset rather than running purely on emotions. It helped us to identify the key variables and maintain a level of control of what initially felt like an uncontrollable situation.

Living in Ambiguity

M A R I L Y N

From a linear perspective, there is only one truth. We can know it, and thus we act as if it is true. If something tells us that our truth is not true, we easily deflect this by saying that whatever is happening is the problem, not our truth. We easily believe that the stories we tell about the patterns we live are accurate reflections of reality. We believe we know what we need to know about the system, so we operate as if we know enough. We believe that the rules are fixed and that there is only one way to work within the system, and we must follow that one way.

I knew I had strong linear thinking tendencies, but never realized just how strong they were. My experience with cancer taught me just how deeply linear thinking was ingrained in my ways of operating. I was shell-shocked and deeply wounded by five months of chemotherapy treatment; now I was in “recovery,” a hopeful place, a place of return. I was convinced that I would now regain my ability to think clearly once again, to walk and run and ride my bike, to visit with friends and family, and to go out for evening events like the ballet. I would be myself again. That’s what recovery meant to me. All I needed to do was to figure out
when recovery officially started. Then I would be on my way back to health and to work.

My last chemo was on July 14, 2009. Add three weeks for the chemo to do its thing. According to my calculations, my recovery would start on August 4, 2009. Instead of feeling sicker and sicker, I would now be feeling better and better. That’s what my oncologist told me would happen, so that’s what I expected.

You can hear the linear thinking in my plans to return to normal. There is a normal life that I have, and I will return to it. I recall talking with my oncologist and saying, “I’ll be back at work by October 2009.” This was my truth, and to me it was the only truth. But, like everything else in my cancer experience, my recovery would prove to be the exception to the rule.

From a nonlinear perspective, truth is an emergent and dynamic property of a system. We cannot know truth, because stories and narratives on which truth rests are socially constructed. The stories we tell about the patterns we live create relational expectations, possibilities, and constraints. We appreciate that we can only understand the partial system, and that stories told cannot be accurate representations of patterns lived. We know little about the system, so we operate as if we do not know everything. We believe that the rules are emergent. The system is dynamic, so we can learn as the system changes. Our learning in turn changes the system, thus creating new rules.

What I had failed to understand was that in my body, in my mind, and in my spirit, something had irrecoverably changed.

Even though my treatment was over and the drugs had supposedly cleared from my system, the damage from the drugs was still expressing itself. Nobody could tell me why I was feeling worse and not better. After all, most people on this form of chemo went back to work within a month of ending the treatment.

Being a person who needs a reason for everything, I went in search of an explanation. When I couldn’t find any, I made up my own. What I think happened to me was something called the cumulative effect. The oncologists talk about the cumulative effect during chemo, in terms of producing cumulative side effects. In other words, the side effects get worse with each treatment. Oncologists are quick to point out that the side effects start diminishing once treatment is over. But what if the treatment did more damage to my body than to most people’s because it is so sensitive? What if my chemo, I would complain bitterly about how ill I felt. It felt as if the chemo was still acting on me well after the infusions, even though I was told that the chemo was flushed out of my system in two days, so I was simply feeling the effects from the damage left in the wake of the drugs.
<table>
<thead>
<tr>
<th>Classic Systems Archetypes</th>
<th>Description</th>
<th>Mental Model</th>
<th>Key Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Limits to Success</strong></td>
<td>Success or growth is leveling off or declining.</td>
<td>“We’ll get bigger and better by continuing to do more of what we are doing now.”</td>
<td>Identify the limit that is causing the decline, then plan for that limit.</td>
</tr>
<tr>
<td><strong>Success to the Successful</strong></td>
<td>Decisions are being made in allocating resources, so that one party is getting attention and resources at the expense of another party.</td>
<td>“Because that person (department, project) is successful, they must be good and others are not.”</td>
<td>Avoid win-lose situations in allocating resources. Find ways to make teams collaborators rather than competitors.</td>
</tr>
<tr>
<td><strong>Tragedy of the Commons</strong></td>
<td>Everyone is using a common resource that nobody owns. Overall usage goes up, but returns to individuals go down. Eventually, the resource may be destroyed.</td>
<td>“This resource belongs to me.” Or “This resource is so vast that it will never run out/collapse.”</td>
<td>Identify the common resource and how people are drawing on it. Then work with users to plan how to allocate and/or limit access to the resource.</td>
</tr>
<tr>
<td><strong>Growth and Underinvestment</strong></td>
<td>We neglect or are unable to invest in the capacity to succeed.</td>
<td>“We don’t need to invest in capacity; we can get through the present crunch by applying greater effort. We can invest down the line.”</td>
<td>Identify the limited capacity that is causing the heroic efforts. Recognize the unintended consequences of the current course of action, then plan to invest in capacity or to deal with the consequences of choosing not to do so.</td>
</tr>
<tr>
<td><strong>Fixes That Fail</strong></td>
<td>All the quick fixes we have tried have worked at first but the problem keeps getting worse.</td>
<td>“Time is money, and neither time nor money should be wasted. Therefore, the first answer must be the right one.”</td>
<td>Identify the quick fix and understand how it has undermined a long-term solution. Take robust actions that solve the problem once and for all.</td>
</tr>
<tr>
<td><strong>Shifting the Burden</strong></td>
<td>We know the fundamental solution, but are unwilling, or unable, to take it, so we implement a symptomatic solution and deal with the side effects.</td>
<td>“We know what we need to do, but it’s too difficult to deal with, so let’s put on a bandage instead.”</td>
<td>Identify the addictive behavior to the symptomatic solution. Then commit to implementing the fundamental solution, no matter how difficult it may be.</td>
</tr>
<tr>
<td><strong>Drifting Goals</strong></td>
<td>We have lowered our standards to close the gap between the actual and desired performance.</td>
<td>“Our current level of activity is acceptable, even though it is below standard.”</td>
<td>Identify the goal and how it has shifted. Recommit to or possibly redefine the goal. Then stay focused on the goal.</td>
</tr>
<tr>
<td><strong>Escalation</strong></td>
<td>Each party sees the other’s actions as a threat and responds in a way that threatens the other.</td>
<td>“We’re under attack or being threatened, and we need to take action to defend ourselves.”</td>
<td>Identify the threat, how it is perceived, and how it is escalating. Then stop reacting to the situation.</td>
</tr>
<tr>
<td><strong>Accidental Adversaries</strong></td>
<td>Each party is doing something that is undermining the other party’s success.</td>
<td>“What that person is doing is preventing me from accomplishing my goal.”</td>
<td>Identify each other’s goals and see how they have put the two sides in an adversarial position. Then seek ways for both parties to accomplish their goals.</td>
</tr>
<tr>
<td><strong>Attractiveness Principle</strong></td>
<td>We are trying to be all things to all people.</td>
<td>“We must please everybody all of the time.”</td>
<td>Identify actions you are taking to appease others. List your own goals, then make choices about what you will do and what you will not do. Stick to your decisions.</td>
</tr>
</tbody>
</table>

Table 2. “Positive” Archetypes

<table>
<thead>
<tr>
<th>Description</th>
<th>Mental Model</th>
<th>Classic Archetype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan for Limits</td>
<td>We identify, evaluate, and plan for limits.</td>
<td>Limits to Success</td>
</tr>
<tr>
<td>Strut Your Stuff</td>
<td>Decisions are being made in allocating resources to give appropriate attention to all parties.</td>
<td>Success to the Successful</td>
</tr>
<tr>
<td>Collective Agreement</td>
<td>Everyone collectively agrees on overall use of a common resource.</td>
<td>Tragedy of the Commons</td>
</tr>
<tr>
<td>Invest for Success</td>
<td>We take actions to invest in future capacity.</td>
<td>Growth and Underinvestment</td>
</tr>
<tr>
<td>Fixes That Work</td>
<td>We identify possible side effects of short-term fixes.</td>
<td>Fixes That Fail</td>
</tr>
<tr>
<td>Bite the Bullet</td>
<td>We are willing and able to invest the time and effort required to implement the fundamental solution.</td>
<td>Shifting the Burden</td>
</tr>
<tr>
<td>Stay on Track</td>
<td>We monitor, evaluate, and adjust performance standards in order to achieve our goals.</td>
<td>Drifting Goals</td>
</tr>
<tr>
<td>Cooperative Partners</td>
<td>We work together and communicate openly for our collective success.</td>
<td>Accidental Adversaries</td>
</tr>
<tr>
<td>Win/Win</td>
<td>All parties pay attention to their own behaviors.</td>
<td>Escalation</td>
</tr>
<tr>
<td>Be Your Best</td>
<td>We have boundaries of what we can and cannot do.</td>
<td>Attractiveness Principle</td>
</tr>
</tbody>
</table>


Body just couldn’t take the cumulative effect that occurred from successive rounds of chemo? What if my body was in breakdown and the side effects in runaway, like a semi-tractor trailer that loses its brakes as it is going down a hill and can’t stop? My side effects were gaining speed and effect, with no exit runaway lane to slow them down. Even though I was no longer receiving chemo, the cumulative effect of six rounds of chemo was still affecting me.

You interpret reality from the stories that you tell, the stories that you live, and the stories yet to be told. These stories are called patterns of meaning and action. When we tell stories about our experience, they help us to make sense of that experience. Often, our stories are not that useful in helping us to understand the system in its more complex sense. But they can help us to cope with situations for which no explanations exist.

By October 2009, I was so sick that my oncologist was unsure as to whether or not to start me on the two-year maintenance treatment. I was nauseated all of the time. I couldn’t walk without the aid of a walker or canes. I was muddled, unable to think clearly, and having difficulty remembering and carrying on conversations. I had debilitating deep-
muscle hip pain. I had severe neuropathy (a numbness in a glove-and-stocking pattern, from my waist down and from my elbows down). I was always exhausted, without enough energy even to get through a day without an afternoon nap. I remember asking whether doing the two-year maintenance treatment would really delay the cancer coming back. My oncologist said yes, but that my subtype of cancer was so rare that no studies had been done on it.

Whether I liked it or not, I was now fully entrenched in the nonlinear world of cancer – cancer treatments, recovery, and something called a new normal.

Henry and I didn’t know what to do. Before our appointment, we had discussed the options. The oncologist said that he wasn’t sure what kind of side effects I would get but that most people don’t get any. It was logical to assume that the side effects would be much less than before, because I was now only taking one drug, not four, and of the four, Rituxin had the fewest side effects. It was a nightmare: there was no certainty, no stability, and certainly no one truth.

I couldn’t find my way back to the comfort of my linear thinking. All I knew was that I was terrified, terrified of the cancer coming back, terrified of going through chemo again, terrified of yet more treatments with Rituxin for the next two years. We had no data on what would happen to me if I received just Rituxin. So, I closed my eyes and jumped. I took the Rituxin treatment. I was so scared during the infusion that I started reacting to it before it even started going into my body. I didn’t realize it at the time, but my body was rebelling. My body was saying no, but I couldn’t hear it. I never recovered, and even though I got a bit better, I never returned to any semblance of normal.

Whether I liked it or not, I was now fully entrenched in the nonlinear world of cancer – cancer treatments, recovery, and something called a new normal. My world had changed forever. Even if I got better, I now lived with an incurable cancer that would return again and again about every four to five years. When it came back, I would be subjected to such withering options as more chemo, radiation, and even a stem-cell transplant, all of which would probably destroy what little life I now had. I had been too sick to be scared during the chemo. But I was scared now. What if I didn’t get better? What if this was now my life? Henry and I still believed that maybe I just recover more slowly than other people. It wouldn’t be until Christmas 2009 that it started to sink in that I was not going to get much better.

In January 2010, I was diagnosed with a second cancer, breast cancer. There’s no question that my world fell apart after the second diagnosis. In January 2011, I entered yet another nonlinear hell. I had been experiencing drenching night sweats throughout August–October of 2010, and night sweats were a possible sign that the cancer was coming back. The CT scan showed that I was still clear of any sign of lymphoma, which was really good news. The bad news was that my neuropathy and lack of ability to walk without aids was now considered chronic. I now had chronic side effects that would not go away.

Nonlinear systems are paradoxical. Ralph D. Staacey, author of Strategic Management and Organisational Dynamics, states that cause and effect and interconnections between agents in the system become unclear because nonlinear systems are very complex. Even though people are dealing with the system as if it were operating under simple cause-and-effect rules (linear), the system is more complex than that and produces contradictory effects. Therefore, complex systems require counterintuitive or nonlinear thinking.

My life has not returned to the old normal, nor has it arrived at a new normal. With no linear thinking left for me to hold on to, I finally surrendered to
the forces of nonlinear thinking. Nothing is as it seems. What worked before no longer works now. The lesson that I have learned is that the longer and harder I hold to my fixed ideas of truth, the longer and harder it is to move forward.

This is true for all of us, whether we are talking about our families or world affairs. Holding on no matter what it costs is a form of linear thinking. Linear thinking works really well when there is stability, but fails catastrophically when there is too much instability. Every day, I watch the world suffocating in its rigid linear thinking as it grapples with an economic system that no longer works. For most people, the answer lies in more of the same and not in something different. Perhaps the world is simply going through its own form of chemo, side effects, and failed recovery to realize that the answers lie somewhere else – in the land of nonlinear thinking.

HENRY
Health issues are generally treated as a problem to be fixed or solved. During treatment, your problem is identified and solved with a protocol. Most times this works, but in situations where these protocols don’t work, you need to consider a nonlinear approach. The nonlinear approach takes into account the whole human, all systems interacting internally and externally.

Right off the bat, Marilyn’s situation didn’t fit the mold. Even when it was clear that certain protocols weren’t having the desired effect, the doctors found it difficult to change the treatment plan. They are trained in a linear mindset, which can be effective with straightforward diagnoses but not as effective when they face unanticipated responses.

We try to approach our lives as learners. In any new situation, someone begins as a dependent learner, moves to being an independent learner, and optimally becomes an interdependent learner, learning in conjunction with others. This applies to children in kindergarten as well as people dealing with health crises.

In a healthcare setting, when you are first diagnosed, you are a dependent learner; the medical professionals walk you through the process of “being fixed,” according to established protocols. If your case is complex, after a while, you find that you need to assume responsibility for learning about and managing your own condition. You become an independent learner. Finally, we’ve observed that when it’s clear that someone can’t be “fixed” and moves to palliative care, the patient and medical professionals become more of a learning team. The patient and the rest of the team become interdependent learners. Both parties are more open to taking a nonlinear approach, to trying small experiments to see what the ripple effects may be. In palliative care, there’s no one formula; it’s a process of action learning. The definition of success – the patient’s quality of life – changes day to day.

Doctors are trained in a linear mindset, which can be effective with straightforward diagnoses but not as effective when they face unanticipated responses.

If you’re open to learning, to trying things, to questioning your assumptions and rationalizations, it makes the journey a lot easier. The truth is, you’re being put in a situation where you don’t have a choice whether to try something new. You can either freeze and not talk about what you’re experiencing, or you can let those emotions come and talk about them – why this is feeling awkward, why it isn’t easy, etc. Letting go and embracing the new takes you to a place you’ve never been before.

The Conscious Unconscious
Marilyn
A new science called “cognitive science” is exploding with information on how humans think and how our thinking gives rise to our behaviors. Cognitive science covers a broad spectrum including brain research, thinking, neurobiology,
The discoveries emerging from cognitive science are challenging the foundation of what we believe as a Western culture and what it means to be human. For example, we now know that our minds are embodied, that most of our thinking is unconscious, and that nothing we think about or experience is emotion-free. This changes the way we consider our ability to exercise free will, and whether or not we can be rational without engaging our emotions.

I have no question that these recent findings are true, especially now, with the experience of two cancer diagnoses, treatment, surgeries, and a protracted recovery. As a result of my first cancer, non-Hodgkin’s lymphoma, I was given the gift of observing what it might be like to die. I was in the hospital, watching myself desperately trying to get enough breath to sustain myself. My lungs were screaming in terror, my chest in shock as water drained uncontrollably off my right lung. It was Wednesday, March 25, 2009, only two days after my first chemo treatment.

I vividly recall having a chest tube inserted into my right pleural cavity to drain the water off my lung. At first, it was all so new to me, something I had never experienced. I had allowed student nurses to be present during the procedure, so a lot of people were surrounding my bed. I was listening to what the doctor was saying and imagining what it all looked like. It didn’t take long before I could breathe easily again, as 2.5 L of water drained quickly off my right lung. All seemed to be going well, and everyone left while I rested. Then suddenly, I was watching myself struggling to breathe. I was no longer in my body. Somehow, I was outside of my body, standing slightly beside the bed, calmly trying to figure out what I should do. I saw myself frantically pressing the call button. I saw the nurse rush into the room and clamp off my chest tube to stop the fluid from draining. I watched everything going on with no fear, no emotion, no curiosity – simply watching and thinking what I could do to help. There was my body flailing, desperate to breathe. And there was me watching as if there was no problem.

In his book, The User Illusion, Tor Nørretranders describes how John Wheeler, a famous physicist, summarized what he believed humans knew about the world. His model is called Wheeler’s U (shown below).

Wheeler believed that the way in which we observe the universe also helps to create it. For example, if we think in linear ways, we will see a linear universe; therefore, we will create a linear universe. When faced with complex nonlinear problems, we will try to solve these problems in linear ways, without understanding why our solutions do not work. If we consider that we are also running in an unconscious mode most of the time, it is small wonder that we cannot seem to solve complex problems or take advantage of complex opportunities. In the situation with the chest tube, I was the observer watching my body (the participant) flailing, desperate to breathe.

But I have also been on the other side, a participant, unable to find the observer in me. When diagnosed with breast cancer less than a year after being diagnosed and treated for lymphoma, the world as I knew it imploded. When the day of surgery
arrived, I lost it. I couldn’t hold onto myself, and I became a crazy person, totally irrational and out of control. I went to bed the night before in tears, crying so hard that I couldn’t breathe. I woke up in tears, needing Henry to help me to get dressed. I cried in the waiting room at the diagnostic center. I cried when I was given a needle with the radioactive tracer. I screamed when the technicians inserted the surgical wire that would guide the surgeon to the tumor. I cried when I got into the car and Henry drove me to the hospital. I cried while I waited to be admitted into the hospital. I cried while getting changed for the surgery. I cried while being wheeled into the surgical waiting area. I cried when the surgeon came to talk with me, and again when the anesthesiologist came to discuss the situation with my leg weakness. I cried and cried and cried, and cried some more. Then the procedure was over, and I couldn’t cry anymore.

*Wheeler’s U* demonstrates the degree to which we are thinking and acting from our unconscious. In their book, *Philosophy in the Flesh*, George Lakoff and Mark Johnson state that most cognitive operations in the human brain are largely unconscious. In fact, it is thought that the estimate now used that 95% of our cognition is unconscious is a *serious underestimate*. They call these cognitive operations the *cognitive unconscious* and describe it as all of the unconscious mental operations and structures involved in language, meaning, perception, conceptual systems, and reason. This 95% below the surface of our consciousness shapes all of our conscious thought. Lakoff and Johnson call this cognitive unconscious a *hidden hand* that shapes the stories we tell about the experiences we have. Superimposing this 95% unconscious on *Wheeler’s U*, you can see that most of our waking moments are actually unconscious. If we are not aware of how much we do that is unconscious, we can find it very difficult to think and act in a conscious state.

That day in the hospital with the chest tube, I think I touched death, or at least the impression of it. As I observed myself, I was “holding death lightly,” as if it were a newborn child lying patiently and contently in my arms. This is an example of melding the observer with the participant in Wheeler’s U, from an unconscious state to a more conscious one.

To find the eye in the storm that has become my life, and to regain some sense of control, I use all of the forms of systems thinking I have available to me.

With the breast cancer surgery, I couldn’t lift myself from an unconscious state to a more conscious one. The trauma was too great, and I succumbed to what was happening, living the nightmare as a pure participant, totally operating from my unconscious. I was numb, unable to breathe, unable to smile, unable to talk. I got better after a few days, but I still couldn’t lift myself into a more conscious state. All I could do was lift the experience into a more conscious state. I could dissect the experience, but I was still completely gripped by the trauma. I kept thinking about how breast cancer is a killer. I couldn’t get it out of my mind. I kept seeing my mother’s face just before she died, writhing in agony as cancer ripped out her humanity and her soul. I was losing my grip on reality, drowning in fear.

To find the eye in the storm that has become my life, and to regain some sense of control, I use all of the forms of systems thinking I have available to me. Any form of nonlinear systems thinking brings
the cognitive unconscious to a conscious level, and with it a sense of control and calm. Systems thinking brings us out of an observer role in a system and into the role of a participant-observer within the system dynamic.

According to Lakoff and Johnson, unless we gain an understanding of the cognitive unconscious, and its effect on our thinking and actions, we cannot easily create new ways of thinking and acting. The key is to bring the cognitive unconscious to a conscious level, to bring us into the role of a participant-observer within the situation in which we find ourselves. Once we are conscious of the fact that we are operating from our cognitive unconscious, we can make choices about what we want to do with this knowledge – how we think and act.

I have few choices now in terms of what I can do with my life. None of these choices, in my opinion, are good choices, and all of them are hard. The trick for me is to be able to live a life worth living, while in the grip of two incurable and advanced cancers, and the side effects of treatment. To me, this means living both the participant and the observer experience simultaneously. I don’t know if I can ever shut off the fear and anxiety that is now so much a part of my life, and deeply embedded in my unconscious. But this cancer experience has shown me that it is possible to hold both places together, as I did when I had the chest tube inserted in my pleural cavity. The participant and observer don’t necessarily cancel each other out. Rather, they find a way to co-exist.

**Endnotes**


**About the Authors**

*Marilyn Herasymowych* is a founder and a managing partner of MHA Institute Inc. If you’d like to know more about Marilyn’s cancer journey, check out her [Cancer Broke All My Pencils blog](mailto:marilynh@mhainstitute.ca).

*Henry Senko* is a founder and a managing partner of MHA Institute Inc. [henrys@mhainstitute.ca](mailto:henrys@mhainstitute.ca)

In 2011, Henry and Marilyn won the University of Alberta Faculty of Extension 2011 Award for Excellence in Program Innovation and Design for Lifelong Learning for their “Leadership Through Learning” program.
I’ve known and worked with Marilyn Herasymowych and Henry Senko as an associate of the MHA Institute for more than 10 years. When I first met them and was introduced to their work in action learning and systems thinking, I was struck by what a difference this type of learning system made to clients’ abilities to think and act more effectively. Applying this work first in the oil industry and subsequently with software companies and government, I was fascinated by its seemingly paradoxical nature: the simplicity of archetypes in contrast to the organizational complexities in which they can be effectively applied.

A New Application

For Marilyn and Henry, Marilyn’s illness presented a whole new arena for application of these concepts. They really do live their work, so it was no surprise to see them turn to the language of systems thinking to try to make sense of their situation. Systems thinking can help people move quickly to a shared understanding of the most complex problems. When Henry said to Marilyn that first day in the hospital, “I guess we better start planning for limits,” they both instantly and intuitively understood what they would need to do to meet the challenges ahead of them. I’ve seen the use of systems archetypes create this same kind of shared understanding in teams, allowing people to communicate recognizable patterns in the system and quickly move to shared understanding and action. Equally important, in situations like Marilyn and Henry’s, archetypes can be very helpful in diffusing emotion, which can be a significant barrier to accessing our unconscious ways of knowing.

One of the more profound aspects of Marilyn and Henry’s learning system is that it focuses on moving forward in a non-linear way through a cycle of reflection and action. Throughout this health crisis, they have remained open to learning and to questioning their assumptions and rationalizations. Continually focusing on both participating and observing has allowed them to freely express their emotions and convey information about what they are going through to family, friends, and colleagues.

I was shocked when Marilyn started sending emails to hundreds of people about her health. She told them what the doctors said, what would happen next, and how it made her feel. I remember the initial email in which Marilyn talked about her first experience with chemotherapy. She described how the treatment cycles worked, how many different drugs she had to take, and how the drugs were designed to both attack the cancer cells and destroy her immune system. She explained that it would be difficult for her to have visitors during the next 6–8 months because her immune system would be so weak. She was on four different chemotherapy drugs plus a host of other medications to control the side effects. Marilyn joked about feeling like a pharmacy and about losing her hair. She talked in some detail about how the drugs made her feel and the side effects.

Archetypes can be very helpful in diffusing emotion, which can be a significant barrier to accessing our unconscious ways of knowing.
At first, I couldn’t fathom Henry and Marilyn’s commitment to keeping us all so well informed with these emails. But I soon came to realize that it was part of the learning process for them. It was such a relief not to have to wonder and worry about what Marilyn was going through. I felt as though I was part of the experience, as if I was on the roller coaster with her. Perhaps that’s why the process has affected me – and others – so profoundly.

**Adaptation Planning**

Throughout her journey, I watched Marilyn vacillate between linear and nonlinear approaches to making sense of her situation. News of a life-threatening illness offers some sense of when or how we will die. It is natural to want more detail, more specifics about how long our life will be and how things will unfold for us. Our usual linear thinking draws us into a certain set of expectations of what “should” happen and how things “should” be instead of giving us the opportunity to become fully conscious of our new reality.

Our usual linear thinking draws us into a certain set of expectations of what “should” happen and how things “should” be instead of giving us the opportunity to become fully conscious of our new reality.

But adaptation planning is different. Instead of planning for a particular outcome or planning for the purposes of controlling future outcomes, adaptation planning is about building our capacity to adapt to uncertain outcomes. It is about developing community resilience, support structures, emergency response, and resources. It is about accepting that outcomes are uncertain, about letting go of our need to find “the” truth or to fix the problem. And it is about understanding that we ourselves are part of the system, continuously changing and adapting in concert with it.

**A New Perspective**

Marilyn’s experience with two cancers and her commitment to learning from the experience both as participant and observer has inspired me to examine many of my own personal experiences from a new perspective. I’ve started to be more conscious of systems versus linear thinking, not just at work but also in my personal life. For example, a systems perspective has helped me reflect on my relationship with my eldest son when he was an infant. I was educated as an engineer and spent much of my career in various project management roles. I approached motherhood as a project and was quite confident that I would be able to strategize, organize, and manage all aspects of this new role in my life. But I was unprepared for the emotional side of motherhood. At nearly one year old, my son was still waking me several times a night and adamantly wanting to nurse, because that’s how he soothed himself.
At the time, I felt as though I was trying everything, but I found it challenging to be consistent. When my son was teething, when we were traveling, or when I was just too tired to do anything else, I would succumb and nurse him, even though I knew I was reinforcing the very behavior I wanted to stop. I found the situation difficult on so many levels – my rational and emotional selves were not aligned, it was hard to communicate the decisions I made in the wee hours of the morning to my (very supportive, but frustrated and sleep-deprived) husband, and I was desperate for sleep. I believed that I was somehow failing to solve this problem, when every other mother in the world seemed to have it beat.

What I didn’t understand at the time was that my son was not a problem to be solved. Instead, I needed to start thinking about him and his sleeping patterns as a mystery to be explored. When I began treating my children as opportunities to learn instead of problems to be solved, my feelings about the situation shifted. It is not wrong to design rules or try different things I read in books, but it is wrong for me to expect my kids to respond in certain ways and for me to feel like a failure when they don’t live up to those expectations. I have learned that when I tell a story about how my children and I have failed, I am focusing on a linear truth, a single solution. Instead, when I am able to openly observe and learn from how we are behaving, I can parent mindfully and consciously.

Through their example, Marilyn and Henry have shown me that when we truly take this work home, inside ourselves, we are able to use our most difficult experiences as human beings to learn from the system in which we are operating, rather than remain a victim of circumstance. When we let go and bring our observer into our consciousness, we empower ourselves by accepting the uncertainty and learn to better appreciate each small moment of our lives.
Change on the Scale of the Whole: Health, Peace, and Prosperity for All

VICTOR GARCIA

My purpose in this article is twofold; my messages are three. It’s my strong desire both to inform you and to persuade you. The messages are as follows: Cincinnati, Ohio, like many urban communities, has a violence problem. But it goes beyond violence, even though that’s the one social issue that dominates the headlines. We have, in a sense, a perfect storm, a constellation of health and social disparities (including violence) whose trends are worsening, threatening generations and impacting the lives of all of us who live in Cincinnati.

Second, our current ways of thinking and responding to these worsening trends not only leave much to be desired, but in many instances have opposite the intended consequence. Third, there is a better way that takes into account the diversity, interdependence, connectedness, and adaptability of the entities involved. Although we have a number of imperatives that threaten the livelihood of a segment of our population and thereby our city, the power and potential of systems thinking and Appreciative Inquiry can transform the city and bring about the sustained, large-scale change of the whole that we’ve been pursuing for decades, if not generations. If you come away with only these three points, then I will have achieved my goal.

Images of a Better Future

I’d like you to take a moment and imagine something. Imagine a world in which we have buildings that actually create energy as opposed to consume it, and that the excess energy that these buildings generate is shared with other buildings. Imagine, if you will, that many commercial buildings are regenerative and produce energy that can then be fuel for other industries.

Imagine corporations like BMW, Nike, and Costco collaborating openly with the World Wildlife Foundation, social institutions, and nongovernmental organizations to bring about a more sustainable world. And
imagine that these organizations are guided by individuals who willingly share their insights and know-how with other organizations and communities that also truly aspire to create a different kind of future.

Finally, imagine that local communities such as Cincinnati offer a multitude of opportunities for every citizen, regardless of his or her station in life, to create value – meaningful, purposeful value. I have come to realize that the poor are some of the hardest working and most creative individuals around. Young people who survive beyond their 20s in the urban core are creative by necessity. In this scenario of a better future, organizations and businesses find a way to harness that ingenuity and aim it in a direction that makes the community as a whole better.

**Disturbing Trends**

I want you to know that individuals and organizations with this kind of vision do exist and are working in Cincinnati to bring about a safe, sustainable community that will provide health and prosperity for all. But let me bring into sharp relief the challenges that we currently face. As recently as 2006, Cincinnati had the dubious distinction of having the highest homicide rate of any city in the state. In fact, the homicide rate surpassed that of Chicago, Illinois, and Atlanta, Georgia. Our homicide rate is still four times the national average. What should be clear by now is that as a society we cannot and will not “arrest ourselves” out of this predicament; the violence persists, despite the number of police officers we put on the streets.

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But what was most disturbing and compelling for me as a pediatric surgeon at one of the world’s most prestigious children’s hospitals – where we pride ourselves on the excellent care that we provide for children who come within our walls – was the nearly 300-percent increase in the number of children coming to the medical center with gunshot wounds. And these were not accidental injuries; they were intentional gunshot wounds. If this epidemic stemmed from an infectious disease, the public would demand immediate action to address it.

What further disturbed me was that we were seeing younger and younger children coming in, in some cases with repeated gunshot wounds. This to me was intolerable, unconscionable, and challenged me to ask what more I could do. It also drew me to the research that contends that urban violence and related health inequities are “social diseases,” arguably more a consequence of the social context where people live rather than of individual deficiencies. When we look at other social trends in our city, we find that we have the highest infant mortality rate in Ohio. There are developing countries with better survival rates for their infants, Cuba being one. An explanation for this state of affairs is related to the homicides and other societal factors in our inner city.

A Perfect Storm
In 1997, Margo Wilson and Martin Daly published in the *British Medical Journal* an analysis of 10 neighborhoods in Chicago suggesting that the neighborhoods with the lowest life expectancy had the earliest fertility. Basically, what that figure shows is that men and women with limited resources, recognizing that their life expectancy was 20 or 30 years shorter than for their peers in most other neighborhoods, were engaging in multi-partner fertility because they didn’t know how long they would live. Life expectancy, economic inequality, homicide, multi-partner fertility, and reproductive timing were interrelated. This multi-partner fertility led to an extraordinarily high infant mortality rate, with some babies being born that were not even the size of a pen. What are the chances of that child living a fruitful and productive life?

To further complicate the picture, the United States has the highest incarceration rates in the industrialized world. We exceed even Russia as a developed country in the proportion of our citizens we imprison. Indeed, we have surpassed
South Africa at the height of apartheid, in terms of the percentage of the population that is incarcerated.

The prison-industrial complex contributes to this perfect storm. An individual who does not graduate from high school has a 50 percent chance of going to prison. Ninety-three percent of those incarcerated are later released, but they’re released with a felony record that permanently changes their lives. In fact, two-thirds of the young men who are released from prison are re-incarcerated within three years, principally because they cannot find work.

This phenomenon of mass incarceration that we find in areas of concentrated disadvantage has now been recognized as one of the major factors that fuel the epidemic of violence in communities around our country. Noted civil rights attorney Michelle Alexander appropriately characterizes it as “The New Jim Crow.” In longitudinal studies, urban sociologist Devah Pager from Princeton demonstrates that when people’s life chances are so permanently altered, it contributes to the perpetuation of poverty, recidivism, and re-imprisonment. Other research suggests that this policy of mass incarceration, which we have embraced with almost fanatical delight, directly harms the disadvantaged communities the policy intends to benefit.

**Breaking the Cycle**

So a perfect storm of high infant prematurity and infant mortality, poor educational achievement, low skills, no skills, joblessness, youth gang violence, and mass imprisonment – along with the related epidemic of obesity and diabetes – is destroying our cities.

Systems thinking gives us a way to look below the surface and beyond the events and patterns of behavior into the system structure to determine the fundamental solutions. A group of us in Cincinnati has embarked on this discipline with the help of Peter Senge, perhaps the foremost thought leader in the practical application of systems thinking and the creation of “learning communities.”

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Through our work with Peter, we’ve learned that the symptomatic solutions we’ve tried to date to combat this negative dynamic in our community merely feed the cycle so that it continues and continues and continues – the quintessential reinforcing loop. Only when we have the courage to “reflect” and “inquire” and have the conscious will to look at fundamental solutions will we be able to break the cycle.

It is our addiction to the quick fixes that has left us in the situation we are in today. You might ask, “Why is it so difficult to bring about sustained change?” I would suggest part of the problem is that we think we’re not part of the system, that the system is out there (especially as it relates to the “ghetto”) and we, as noble change agents, are here to fix the problem. When we excel at seeing the system, we come to recognize that we are part of the problem. And only when we’re able to look at our role as contributors will we be able to bring
about an open awareness of what’s possible and will positive changes begin to take place.

**What Is Good Health?**

So the question arises, then, “What is needed to achieve good health?” Sociologists suggest that good health is not really about healthcare. Research shows that a population’s health is largely embedded in the social and economic environment. This finding means that health is not just about medical care or the quality of health within a hospital. Good health means housing policy. Good health means educational policy. Good health means economic justice and economic self-sufficiency. Good health means an antiviolence policy that is based in systems thinking. Sociologists have long recognized that health campaigns focused solely on changing individual behavior are naïve because individuals’ choices are most often limited by their social context.

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With humility and some vulnerability, we have come to acknowledge that too many of our fellow citizens in Cincinnati are not benefiting from or contributing to a healthy, prosperous quality of life. As a consequence, we all suffer.

And so the question further arises, “How do we make an unhealthy neighborhood healthy?” Based on our new understanding of systems thinking, I would submit that it’s not with quick fixes or symptomatic solutions, but with what we refer to as “change on the scale of the whole,” which then further begs the question, “Can it occur? And can it be sustained?” Through a series of brilliant accidents, necessary failures, attempts to bring about sustained change, and improbable breakthroughs, I’ve come to the conclusion that change on the scale of the whole is not only possible, but it is possible in our lifetime.

**A “Brilliant Accident”**

One of the brilliant accidents I experienced was meeting Peter Block, who introduced me to John McKnight and his theories on asset-based community development, to Byron White, who at the time was vice president for University Engagement at Cleveland State University, and to Peter Senge, who in turn introduced me to David Cooperrider. David Cooperrider is the founder of a field of practice called Appreciative Inquiry. The consequence of this series of events was an immersion in systems thinking and related disciplines, and an understanding that, in order to bring about sustained change, we need to develop three core learning capacities:

- seeing systems and our role as part of those systems,
- collaborating across boundaries in a way that has not been done before and typically cannot be done without some particular skills, and
- creating the desired future, not problem solving or reacting to the crisis, but envisioning the future that we desire for this city.

We designed – and continue to design – initiatives based on systems thinking and Appreciative Inquiry to engage all the stakeholders in Cincinnati. All corners are represented. Everyone is convened. Everyone is at the table. And everyone is involved in a generative, empathic conversation about the future.

Appreciative Inquiry is different from most other, if not every other, change initiative, 90 percent of which ultimately fail. The reason Appreciative Inquiry has resonated with people, not only globally but with those of us in Cincinnati who are working on this initiative, is that it is asset based. This means that we look at the positives in the individual, in the community, in the neighborhoods,
and in our city. And we leverage those so that our strengths then surpass our weaknesses or, as Peter Drucker says, our weaknesses become irrelevant. Together, Appreciative Inquiry and systems thinking frame the focus that inspires the entire community and motivates all stakeholders to work toward creating this vision of a safe, sustainable Cincinnati. As Peter Block has taught us and long espoused, through conversations that matter, we can transform this vision into a reality.

We acknowledge that it will take a sustainable systems approach to bring about the kind of changes that we desire. We can accomplish this outcome in our lifetime by collaborating in a way that has not been previously achieved. As a first step in this journey, in 2010, we organized a workshop based on the Appreciative Inquiry methodology.

Initial Steps with Appreciative Inquiry

David Cooperrider pioneered Appreciative Inquiry (AI) at Case Western Reserve University in Cleveland, Ohio. It has been applied not only in individual communities throughout the country, but in nations throughout the world. In addition to its application in business settings, it has been used to address issues ranging from large-scale ecological challenges to social issues such as poverty.

Appreciative Inquiry is distinctly different from more traditional approaches to change. Rather than focusing on solving problems, AI looks at the community as a living system and in so doing focuses on:

- appreciating what gives life, what’s working, and what’s best;
- imagining what can happen;
- designing what might be; and then
- creating what will be.

We are so focused on the negatives within a community that we don’t realize that, within that same community, enormous strengths exist.

On September 11, 2010, David Cooperrider and Peter Senge hosted a workshop at the Cintas Center at Xavier University in Cincinnati. Initially the event was supposed to involve 70 people, but it grew to 120. We had to turn individuals away just because of the limited room capacity. Participants learned how to harness the power of systems thinking and Appreciative Inquiry to create the
future that we all want. They learned about what we currently know about change in human systems, especially change on the scale of the whole, which so many people think is improbable. And they took away lessons and insights about what it really takes to collaborate at a systems level.

At this workshop, we had CEOs listening intently. But we also had gang members, former gang members, community residents, and community activists listening equally intently. More important, and what I found most touching and poignant, was that these individuals were talking with each other, not at each other. They did so in a generative, empathic way, understanding the limitations of the human condition and with the knowledge that what we say and what you hear are not necessarily always the same.

Once we got everybody to appreciate – or at least exposed them to – the concept of systems thinking, we transitioned into the power of tapping our inner strengths. We are so focused on the negatives within a community that we don’t realize that, within that same community, enormous strengths exist. How can we tap those? How can we help these inner strengths erupt like a volcano, in a positive sense, to create our vision of a better future?

It was just extraordinary to see the energy, engagement, and commitment on everyone's part. As Byron White says, “Every single person brings gifts, talents, experiences, and insights that are necessary for us to be successful.” This event underscored how promising the future is despite the daunting challenges we face.

**Quotes from Summit Participants**

**Peter Strange**

“It will be impossible to be a high-end builder in communities where people don’t want to invest. In order for us to have a future, we’ve got to be part of creating vibrant economic environments where every citizen has the opportunity and the motivation to be part of value creation.”

**Carl Satterwhite**

“We have to think differently. Because the reality is that we do have to give these young people some opportunity. It don’t matter how big the wall, how big the gate, no matter how we are in our own communities. It’s folks who don’t have coming to get. And eventually, they’re going to stop trying to get it from each other, and come and get it from us who have. So we’ve got to try to work with them.”

**Doug Hall**

“We’ve got to get jobs, straight up. People need jobs. But we’ve got to give them jobs that have a future.”

**Joe Prather**

“We’re used to people always coming to the neighborhood house and telling us what we should do and how we should do it. So we’re like, ain’t about to go here and listen to what they’re telling us what we should do. They don’t even know us. We’re from two different sides of life. To change the city, you have to change the youth. Because a lot of the older people are already set in their lives. And how you change the youth, you don’t tell them what to do. But you help them at what they want to do.”

**Appreciative Inquiry Summit**

In February 2012, Peter and David, along with Mark Chupp of the Mandel School of Applied Social Sciences at Case Western, facilitated the Core Change Summit. The Core Change Summit drew more than 500 residents and leaders who normally don’t work together to address the greatest challenges in the urban core. The ultimate goal is to increase employment, educational achievement, and safety in Cincinnati’s core neighborhoods while improving residents’ overall health. Support for the program came from organizations such as Cincinnati Children’s Hospital Medical Center, United Way, Xavier University, the City of Cincinnati, Urban League of Greater Cincinnati, Cincinnati NAACP, Cincinnati Public Schools, STRIVE, Elementz (a center that works with neighborhood youth), and local chambers of commerce.

With the Summit serving as the “crucible,” some 15 action teams continue the work of enabling
The ultimate goal is to increase employment, educational achievement, and safety in Cincinnati’s core neighborhoods while improving residents’ overall health.

Gathering “Our Best Minds”
We find ourselves today grappling with the same conditions that were brought to the surface as far back as 1899. W.E.B. DuBois, one of the first civil rights activists and sociologists, refuted Frederick Hoffman’s claims that Negroes in Philadelphia had mortality rates higher than the white population because of their immorality, intemperance, and racial inferiority.

Combining scholarship and fervent advocacy, DuBois demonstrated that if the economic and
social disparities and inequalities were addressed, the lifespan of the Negro infant would be extended and approach that of the majority population. Where we live, where we work, and the neighborhoods where our families reside are more potent determinants of our life and longevity than germs and viruses. In his 2007 commencement address at Harvard, Bill Gates, Jr., asked, “Should our best minds be dedicated to solving our biggest problems?” He did not pose this question in a rhetorical fashion, but rather meant it as a sort of challenge. My wish is for the best minds in our city to join me and others to deal with some of Cincinnati’s – and our country’s – most vexing and seemingly immutable problems.

ADDITIONAL RESOURCES

Video of Victor Garcia at TEDxCincy

ENDNOTES

