

The Nature of Narrative Medicine

By Lewis Mehl-Madrona, MD, PhD

*The sufferer is a poet in search of metaphors
adequate to express his predicament*
—Laurence Kirmayer, MD¹

Speaking to Share Story

“When we speak, we usually speak *to* others and we speak *about* something (or *about* others)—and we do both at the same time, and by use of discursive means (such as lexical devices, syntax, ... and gestures).”² In essence, we tell a story—short or long. Our conversations are full of vignettes and tales, as are our diversions and entertainment.

Medicine is no exception. When we physicians speak, we speak to each other, to our patients, to representatives of insurance carriers, to administrators, and even to our own family members. When we practice medicine, we are always speaking about something—a patient, a particular medical problem, a procedure, a drug, our own frustrated emotions. And, we are in constant communication with each other and our patients. We are interacting. We are shaping a world as we go. We are using discursive methods to convince others to do things—patients to stop smoking, insurance carriers to pay, administrators to let us have more time with patients, family members to be more understanding about our hectic lives. In this respect, we are no different from healers the world over, though the content of our conversations may vary. We may talk drugs while Bantu healers talk herbs. We may talk surgery while a Dene healer talks about a many-day Blessing Way ceremony, but there is a similarity: we are in dialogue. We are co-creating a shared story of healer and patients/families/communities wherever we go. We are immersed in the art of storytelling.

Constructing Story

Kathryn Montgomery Hunter (1991) has written a wonderful book³ about the narrative structure of medical knowledge. She notes that the ancient craft of physicians and healers involved “... pondering the ways that predispositions and circumstances meshed

with the laws of nature in a particular case”³ and in encouraging the patient toward recovery or midwifing his or her progression toward death. This approach is not unlike that of traditional North American healers, whether the circumstance involves a curse or the breaking of a taboo or a spiritual attack. Healers construct stories that have beginnings, middles, and ends about people with predispositions who encounter circumstances that lead to illness, progressing toward recovery or death. Medicine’s fascination with eliminating the person from this process and talking about the “natural history of disease” as if it existed independently of the people who suffer with the disease is part of the reification of the *disease process* into *disease entities* that has happened in the 20th century and continues into the 21st. We forget that we are still telling a story when we talk about an organ as much as we are telling a story when we talk about a person. The elements of the narrative remain. The characters differ.

Stories have characters who act in space and time within a plot. Stories are ideally performed as is the case for any oral tradition. They are creations or constructions. The histories that we physicians take are actually stories told by our patients about their suffering. The characters (patients, family members, other physicians) interact within the plot of diagnosing and curing the illness. Various saboteurs and adverse circumstances exist to potentially foil the plot and affect the happy ending. The story is enacted in each medical encounter to the extent that time and the doctor’s temperament will allow. And, even when the story is not fully presented (or is *re-presented*), it lies beneath the surface of the encounter, unexpressed yet just as powerful.

Changing Your Story

An example will help illustrate this concept. Terry is a woman, age 44 years, with a 24-year history of severe, relatively intractable, irritable bowel syndrome (IBS).

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Lewis Mehl-Madrona, MD, PhD, is a family practitioner at the West Winds Primary Health Centre and an Associate Professor of Family Medicine and Psychiatry in the College of Medicine at the University of Saskatchewan in Saskatoon, Canada. Dr Mehl-Madrona provides psychiatric services to the Athabascan Health Authority in Stony Rapids, Saskatchewan, serving Black Lake First Nation and Fond-du-Lac First Nation. E-mail: mehlmadrona@aol.com.



Terry came to see me because she had tried every conventional and unconventional approach to IBS and none had worked. She had been to gastroenterologists, the Mayo Clinic, the Cleveland Clinic, the local general practitioner, naturopaths, homeopaths, acupuncturists, herbalists, kinesiologists, psychic healers, shamans, energy healers, reiki masters, chiropractors, osteopaths, and more. The center character of her story was IBS, perhaps even more central than she in her initial narrative. What was remarkable was how appreciating and helping her change her story about herself allowed her IBS to greatly improve. Physicians do not usually pay attention to the person's life story, and perhaps we should.

In a narrative approach, the identity of the person is a "master narrative," a composite of all the stories that the person has accepted and repeated about him or herself. Sometimes we are only vaguely aware of the source of some of the "morals of the story." We can remember the point and forget the source.

Through a combination of guided imagery, dialogue, and ceremony, Terry's story emerged. She remembered being a seventh grader in a Catholic School and being very angry at God. She had learned to view God as a white-haired old man on a throne in charge of everything. She was angry at God for not making her life and her family's life better. She thought if she were only more perfect and better behaved, God would smile upon them and make things better for them. This idea seemed to pervade her life—that God would reward you and take care of all the problems in your life, if you are only good enough. We found a five year old suffering under these beliefs as well as a three year old, barely aware of the concepts yet comprehending the injunctions to be perfect. We went looking for other important characters in her internal mental world—characters who were telling stories that affected her life. One, whom she labeled the Saboteur, did everything possible to keep her from being happy because: "You don't deserve it. You haven't earned it. You aren't good enough to be happy." She began to reflect on the voices of all her relatives as she grew up; the meaning behind the stories they told her, their notions of life, their misery and pain. These characters resolved into those relatives and their stories that supported the ideas that she had internalized. The message she learned was "Be like us. Be unhappy. Day after day, life is the same old thing. Life is drudgery. You

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live for retirement; then you retire; and then you die." How depressing, she thought.

The other theme underlying the stories with which Terry grew up was the security theme. Her parents were children during the Great Depression and therefore insisted that security was the ultimate value and goal.

Terry was admonished against ever taking a risk, however small. She realized that she didn't have IBS until she began working as an IT (computer) consultant, a profession that she hadn't wanted, and only took because her parents insisted that it was secure. She remembered her mother scaring her into being dependent, living at home, not venturing out into the world. She dreamed of escaping. She recalled everyone in her family throughout her childhood saying, "No, you can't (won't, don't, etc). You can't do anything unless you're perfect first." These voices included her mother, maternal grandmother, maternal grandfather, father, and seventh- and eighth-grade teachers.

When we countered this story and co-authored a different story about being able to follow her passion, being able to take risks, and not needing God to fix her, the IBS began to change. Her symptoms improved as she became someone different from the voices left behind by her family. She re-evaluated her job and found a different position in which she had less pressure and responsibility, and could be more creative. She re-evaluated her relationship and broke with a boyfriend who was barely working and was living off her. She began to explore traveling and reached out to a new set of friends who were more spiritually inclined. Several months into this process, her IBS symptoms were gone. This was not magic, just attestation to how our lives and our illnesses are inseparably interwoven. We cannot treat illness without considering the lives and stories of those people suffering from those illnesses.

Constructing Our Truths in Story

Stories are made for audiences, and that is the role of the physician—to be a good audience, to help rewrite the story toward one in which healing seems more plausible to the patient. The physician must also be a storyteller and a healer. This is because people's illnesses are grounded in *discourses* or stories which contain the meanings and values which we live.^{4,6} Culture and experience helps us to weave a coherent thread out of the many sometimes contradictory voices that bounce off the insides of our head.

Illnesses are part of the identities that we perform.^{7,8} They make or mark us as we wish or are wished to be

seen. We evolve through our relationships and interactions with others. Illness is dynamic because we are dynamic. Some changes improve illness; others worsen illness. Patients and doctors position themselves with each other through their interactions. Through the doctor-patient dialogue, patients learn how to be patients, what to expect from life with an illness, and how to approach their illness. The conventional paradigm takes all accountability away from the sufferer except for taking medications as prescribed. The life story is not explored. Unfortunately, expectation is important in predicting outcome. A pessimistic expectation leads to a more pessimistic outcome. The “patient’s story” has huge effects on the course of the illness.

Narrative approaches rely more on the expertise and resourcefulness of the sufferer than does conventional medicine, which relies on the expertise of the practitioner.⁹ Narrative approaches resemble what has been called eclecticism or integrationism in psychotherapy circles.¹⁰ Norcross described synthetic eclecticism, which attempts to synthesize many perspectives into one unifying theory, and technical eclecticism, which picks and chooses from various techniques without any need to accept the theory that generated these techniques. Integrationism strives to put together different schools of psychotherapy. What differs about these approaches is the assumption that there is a truth that can be discovered. Within a narrative approach, we realize that we are constructing our truths in story form because we simply cannot live without beliefs (truths) and we cannot function without making up stories to contain those truths. We explain our beliefs to each other by telling stories about how we came to accept these ideas. Some of these stories are highly technical, as in a biochemist explaining how he came to understand the structure of a receptor, yet they are still stories. They have temporal sequence; they have plot; they have characters; there is a logical movement through the story; and a value is discovered at the end (good science prevails). The value of the narrative perspective is its relevance to biological as well as psychological phenomena. When we realize that we are inevitably telling a story, even if that story is a mathematical proof, then we have a common language to move from field to field. Even if I do not understand the elements of the proof, I can appreciate the temporal movement of the argument; I can appreciate that the variables are the characters; I can appreciate that the mathematician is the narrator. I can see the plot unfold until, like a suspenseful murder mystery, the conclusion proves the theorem,

and all is well in the world. Epidemiological investigations read the same way. All human communication is storied, even our communication with ourselves (what cognitive therapists call self-talk).

Why Does this Matter?

When we see the story behind people’s actions and statements, we can bring tremendous resources to bear on the problem. This is because we are all experts in story construction and interpretation. We have been doing it for longer than we can remember. We critique movies in accordance with the quality of the story. We tell stories about friends and colleagues. We read novels, attend plays, struggle to make sense of operas, and generally are immersed in story. When we understand that all problems, even cancer, are storied, we have many more resources to help us understand them.

How is Cancer Storied?

In its most simple form, cancer is a story about the rebellion of a single cell from the whole. A single cell mutates or is changed in some way and begins to replicate those changes. A drama occurs in which the immune system fights those changes and loses. The cancer spreads to clinical recognition. Then begins a human drama in which physicians use all the means at their disposal to attack and kill the cancer cells. Sometimes this kills the patient as well. Sometimes the patient mysteriously recovers. Sometimes the patient succumbs to the cancer. All this occurs in a context—on a stage, to paraphrase Shakespeare. When we see cancer as a story, I think it’s easier to see the potential interconnectedness of everything. For example, some people miraculously recover from cancer. My friend Alice is nine years cancer-free after a diagnosis of glioblastoma multiforme. This is highly unusual, though, because of my interests and lectures, I know a number of other people who are in her situation. Andrea’s story is one I never tire of telling. And, when I tell it, I mention the huge role in her recovery played by the large and amazing changes that she made in her life, her relationships, her work, and her spirituality. That’s my story and hers as well. I don’t downplay the chemotherapy and the radiation therapy, though I know from the data at the time of her diagnosis that

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these modalities were only expected to prolong her life by 4%. Every one of the patients who died received these modalities, though not all the patients who lived did. When I tell Andrea's story, I can keep it as a story. I don't have to explain exactly why it happened. I can make a meta-story which goes like this: some people make huge changes in their lives and these changes have physiological consequences and their cancer disappears. Can I predict in advance who these people will be? I have made such predictions, though I'm not entirely sure on what I base them. A neurosurgical colleague, Allen Hamilton, MD, of the University of Arizona, told me he could predict surgical outcome for brain cancer on the basis of the number of people present in the room at the first appointment, how many hugs he got before he left the room, and how much his mood improved while he was in the room. I think I can predict who will not have a miraculous recovery with better than chance odds. While transformation is unpredictable, the results of pessimism and despair are not. What I cannot understand and can only describe in story, is the process that people go through to arrive at the personal and interpersonal transformations that change lives.

Could any of us accomplish this? Few of us have been so challenged, and so we don't know of what we are capable. This is where healing and recovery and their associated stories lack the capacity to be replicated on command. There is a mysterious, somewhat hidden process of transformation that involves shifts in multiple relationships and is perhaps better addressed through the principles of quantum physics than the classical mechanical, cause-and-effect models that are so familiarly used by us.

Story or Evidence

Here is another story. My friend Bernard developed a malignant astrocytoma (a brain cancer). We shared Andrea as a mutual friend. Bernard had seen what radiation therapy had done to Andrea's cognitive capacity. He was a professor of mathematics and engineering. That was his passion. He would rather die than not be able to do mathematics. He declined radiation therapy. He had two injections of chemotherapy and decided that this would destroy his life as readily as radiation. He threw himself into making all the changes that we had seen Andrea make. He left a bad marriage. He fell in love. He quit his job that bored him and found a more exciting position a continent away. He returned to his homeland where his love lived, where he was surrounded by family and support. He had most of the cancer removed, but not all could be safely taken.

It disappeared over the next two years and he is now seven years cancer-free. What a story!

Does it prove anything? Not in our usual hierarchy of evidence from the evidence-based medicine movement. But maybe that movement has missed the boat. It values most the evidence that is sometimes of limited clinical significance. If I have two drugs to prescribe, then I turn to evidence-based medicine to learn which is the better of the two for the patient I am treating (unfortunately, most drug studies have such rarified patients that I almost never find a study applicable to the patients I treat because they are far sicker and have more illnesses and other difficulties than study patients would ever be permitted to have.) If I want to ask the question, can people survive cancer, then I turn to stories like Andrea's and Bernard's. I say yes they can, but under conditions that are somewhat mysterious and hard to duplicate. That leads me to tell stories to patients, to inspire them to make their best effort. I have confidence that when they make that best effort, the ensuing meaning and purpose that results, the story that they and their family eventually tell about their challenge of cancer, contributes to a better quality life whether they live or die. If healing involves transformation and improvement of potentially every aspect of one's life, from the spiritual through the relational to one's own body, then, by definition, quality of life will improve through efforts at healing, even when the disease is not cured.

Meaning and Purpose

Perhaps this is the essence of narrative medicine—of appreciating the rich stories we have gained in our training, of appreciating the stories our patients and their families bring us, and of seeing ourselves as coauthors in the creation of new stories that have uncertain endings, at least while they are being written. Let us be eclectic in the sense of applying treatments that make sense within the story lived by our patients and their families. Let us be cognizant of our own "truths" as being just preferred stories for our lives, and not necessarily the gospel, even when our truth is the Gospel. Let us interact with people to foster transformation, to increase a sense of meaning and purpose, to weave together a rich tapestry of human lives, and within that story, let us rely upon evidence-based medicine to pick the best drug when we have a choice, but not to tell us that being human and collaborating in the richness of life has no value, when we know from our own stories, our own illnesses, our own life challenges, that it does. ❖

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To Be Well

To wish to be well is part of becoming well.

— *Lucius Annaeus Seneca, 3 BC-65 AD, Roman dramatist,
poet, philosopher, and orator*