In the end, we realize that although Ivan Ilych's experience of dying was terrible, he arrived at an understanding that to live meant not only to love and be loved, but also to remain true to one's beliefs—even against social and business pressures to do otherwise. Despite Ivan's earlier conviction that he had only done what society expected of him, he came to the conclusion that his previous beliefs about what constituted a good life could not transcend his experience of suffering and death.

Perhaps in Vasya, Ivan Ilych saw himself before he was enticed by society. Or maybe it was Gerasim's unselfish influence that led to Ivan's transformation. Whatever the reason, he seemed to become a new man, capable of giving and receiving love. With his terrible burden of doubt lifted, Ivan Ilych was able to grieve for his son's emotional pain and to make peace with his wife. Gone was the fear of death, and Ivan was able to free himself from his tortured body (279).

Telling Our Stories: A Process of Integration for Patients

by Peg Stokman

We are just beginning to question, much less fathom, how and why we heal. This essay explores the power of storytelling as a key agent in the healing process. Telling stories allows patients to reflect on their lives and identify their unique contribution to the world. A person must be able to integrate illness into his or her life in order to learn from it and finally to accept it. The narrative model brings to light the deeper level of suffering involved in illness. Trust and confidence between patient and caregiver are built on shared storytelling.

> Healing means, first of all, the creation of an empty but friendly space where those who suffer can tell their story to someone who can listen with real attention. Healers are hosts who patiently and carefully listen to the story of the suffering stranger. Patients are guests who rediscover their selves by telling their story to the one who offers them a place to stay.[1]

"I haven't been to the doctor for two years since our visit in the ICU."

"I've changed doctors since I saw you. This doctor takes time to listen to me."

"Can you believe this! The surgeon made a diagnosis by looking at a chart. He never stopped in my room to see what I looked like."

"I'm in here because of a broken heart since my husband died, and no test will show that."

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A chaplain and a doctor offered hospitality to two patients and healing took place. The other two patients felt devalued and angry because their doctors did not take time to listen to them.

Telling our stories is a powerful process for integration and wholeness in all of life, but especially for patients. Illness forces one's world to shrink. Storytelling helps one's world to expand beyond the immediate. For the terminally ill, reflection on their lives pulls together the significant parts, giving them a chance to identify their unique contribution to the world. In acute care, the physical and emotional isolation of a hospital provides an opportunity for a patient to do the necessary work of integration with his personal story. Removed from his support system and the distracting busyness of everyday affairs, the patient has time to listen to his life, not as isolated events but as a continuum linking past and future with the present. This process of integration softens the feeling of isolation.

I would go so far as to say that storytelling is medicine. "Always in emergencies we invent narratives. Storytelling seems to be a natural reaction to illness. Stories are antibodies against illness and

one's story helps ennoble and empower patients with a restored sense of personhood, which is necessary for the healing process.

Storytelling actually is a return to the original philosophy of medicine, a biopsychosocial model, proposed by physicians such as Sir William Osler, the founder of bedside medicine. Osler believed that it is much more important to know what sort of patient has a disease than to know what sort of disease a patient has. Discovering who a patient is affects every aspect of disease including symptoms, healing potential and recurrence. How a patient talks about his life will tell a doctor more than disconnected, objective facts.

Illness forces one's world to shrink. Storytelling helps it expand beyond the immediate.

This renewed attention to the importance of story in medicine appears to be a grass roots effort, born out of the felt needs of patients, philosophers, ethicists and some physicians. Also, change is occurring because people are reacting to rational, scientific medicine which emphasizes tests and technology. Patients and philosophers argue that the biomedical model shows less respect by not caring for the whole person. Can any technology explain what it means for a woman to have a hysterectomy at age twenty-three or for an elderly patient who has lost her will to live to be subjected to another round of tests? Doctors and scientists defend with cries of lack of time and the need for certitude in test results, both in making a good diagnosis and for legal protection. Doctors report that it is difficult to find a balance between competency and bedside manner that satisfies patients.

As a hospital chaplain, I frequently feel caught in the middle of this conflict. While patients are my chief concern, I try also to listen to physicians. Nurses and doctors envy the time I have to connect with patients, saying this was a primary motivation in entering their professions and a major frustration in their work. Chaplains also have an edge in quality patient visits, I believe, because the diagnosis is already made and not our chief concern. From my perspective, a chaplain's main role is to bring an empathetic presence that enables patients to tap into strengths they will need throughout their illness.

If we believe that each person holds unique worth, that the most vulnerable among us deserve special care, then it is a true ethical concern that patients be treated in a manner that affirms their value as persons. "Just as he orders blood tests and bone scans of my body, I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some such recognition, I am nothing but my illness."[3]

The biomedical model views medicine as a science, focused on the biology of disease. It is patient, rather than person, oriented. Distinguishing between a patient or person focus is relevant because a patient can be easily—and mistakenly—equated with his disease. A person is more than his illness. Lack of attention to the interplay of body, mind and spirit lessens respect for the whole person. The biomedical model can turn the patient into an object of professional inquiry and manipulation. Technical procedures may be substituted for moral acts.

The biopsychosocial model says, "Medicine is not a science. Instead, it is a rational, science-using, inter-level interpretive activity undertaken for the care of a sick person."[4] It is person, rather than patient oriented. This diversified model stresses the meaning of illness as it affects the whole person. A patient must be able to incorporate the illness into his life in order to learn from it and finally to accept it. The biopsychosocial model attends to the deeper level of suffering involved in illness. In my judgment, it is the most ethical model for medicine.

"How the physician listens to the patient's story of illness indicates how he will talk to the patient about the disease and participate in the drama of healing."[5] Good communication between patient and doctor is key. When a patient is able to see his doctor as a partner in healing and not as a god who makes him well, both are satisfied. My sense is that much of the anger and some lawsuits result from unsatisfactory communication where a doctor is viewed as an antagonist. Patients report that when doctors keep them in the dark about what is going on by not answering questions or by neglecting to give clear explanations about procedures, it is difficult to trust that your doctor is for you.

On the other side, patients can be viewed as antagonists to the doctor. Doctors report that patients are more demanding, warning that if you don't do things their way, they will find another doctor. A health article in a popular magazine can have more authority than the doctor's judgment.

There are many ways patients can tell their stories. However, the case history is the basic medium of storytelling between patient and doctor.

The interview is the source of primary data essential for the work of diagnosis even in the era of computerized taxonomies and nuclear magnetic resonance images, and the act of "taking a history," passive and transparent though the phrase assumes it to be, is part of the construction of a distinct medical narrative.[6]

How sensitively this dialogue is conducted affects the entire process of healing. Patient and doctor are both storytellers and storylisteners in the case history dialogue. It has four parts.

The patient tells her story, the physical symptoms that alerted her to her illness. A patient complains that she is tired all the time, that her heart feels like it is racing. The doctor listening with empathy, in solidarity with the sick person, is the first contribution to medicine's healing task. He or she must also listen as critic, picking out significant facts from symptoms for testing and diagnosis. Secondly, the doctor interprets her story, using the signs he observes and the story of symptoms. It involves listening not only to what a patient tells but also to what she doesn't tell or can't tell. Perhaps, if the doctor asked about what else is going on she would tell him that her divorced daughter and her two children have moved in to make ends meet. Next, the doctor becomes storyteller as he retells the story back to the patient, adding his medical version. This story enters the ongoing life of the patient. "Whether he wants to be or not, the doctor is a storyteller and he can turn our lives into good or bad stories, regardless of the diagnosis."[7] Lastly, it is the patient's story again. The patient can rewrite her life story by considering the changes she needs to make in order to bring about improved health. These decisions are the patient's responsibility, but the physician can help by staying involved in the process. If a physician does not pay attention to the patient's story, he gives up an honest relationship based on trust. He gives up the wisdom that comes from knowing people—their personality, cultural patterns, religious beliefs, support systems, and expectations of self and physician. He misses the connection with the patient's spiritual center.

Much can be lost in the exchange of stories during a case history. The physician may not take seriously what the patient experiences, as with the woman who said she was in the hospital because of a broken heart. Or the physician might not consider the whole story. Mildred, age 70, complained, "The physician is dismissing me today and I don't feel strong enough. I think I could be ready with one more day. He doesn't seem to remember that I was caring for my husband before I got sick. Now how are we going to manage?" The physician did not acknowledge, to her satisfaction, the life story out of which she came and to which, well or ill, she must return.

Robert, age 35, had been admitted several times for persistent stomach pain over the past six months. He was so angry when I entered his room. His wife was in tears. All morning he had anticipated a visit from the surgeon called in on his case. The surgeon "visited" Robert's chart but not Robert, basing his diagnosis on the chart and case history prepared by another physician. The nurse had informed Robert of the surgeon's diagnosis just minutes before my visit. "That physician didn't even care enough about me to walk fifteen feet to meet me or check my body." It was the breaking point for him. "Perhaps nothing is more frustrating or humiliating than being neither seen nor heard."[8]

Osler believed it is more important to know what sort of patient has a disease than to know what disease a patient has.

Physicians with whom I have spoken agree that it would be valuable to add two statements to a case history: (1) The patient's understanding of illness. (2) How that illness affects a patient's life. Taking time to elicit the patient's responses can contribute to the healing process.

> I wouldn't demand a lot of my physician's time. I just wish he would brood on my situation for perhaps five minutes, that he would give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way.[9]

Documenting the person's psychosocial needs on a history will facilitate a multi-disciplinary team approach, resulting in better care. This is the most effective way to involve the person in his or her treatment and allay any feeling of abandonment. Broyard found a physician who became a "Virgil, leading me through my purgatory or inferno.[10] One senses that the doctor's support played a big part in his ability to describe his illness as "intoxicating." Broyard was energized by the challenge of developing his own style of illness, jaunty and witty.

Attentiveness to well-rounded case stories also helps both physician and patient understand the

deeper layers of suffering. Pain is not equated with suffering. A patient explained that the pain of her cancer is nothing compared to the pain of feeling abandoned by friends who don't often come to visit. A high school senior, hospitalized with knee surgery, dealt with her broken dreams of being the soccer team captain and participating in a state championship dance troupe. Pain is an unpleasant stimulus caused by an illness. It is most commonly described in physical, bodily terms.

Suffering is pain on a deeper level, experienced as a threat to our composure, our integrity, our sense of completeness. Our bodies fail us, thus we need to deal with imperfection. The unexpected interruption caused by illness threatens the harmony of life, our sense of control. Suffering can include a feeling of unfairness, "But I'm so young"; injustice, "I can't find insurance"; victimization, "He was the smoker, not me"; insult, "I've always taken such good care of my body"; and loss of control, "I manage a company. Here everyone tells me what to do." A key to healing is making sense of suffering, discovering its meaning in my life. Broyard describes his experience as a patient with terminal prostate cancer and explains why he needs to talk to his doctor about suffering:

> I would like a physician who is not only a talented physician, but a bit of a metaphysician, too. Someone who can treat body and soul. There's a physical self who's ill and there's a metaphysical self who's ill. When you die, your philosophy dies along with you. So I want a metaphysical man to keep me company. To get to my body, my physician has to get to my character. He has to go through my soul. He doesn't only have to go through my anus. That's the back door to my personality.[11]

Pain is the first thing a patient will discuss. Going deeper into suffering often requires more trust in the relationship, sometimes silence, sometimes open-ended questions.

Silence and knowing someone cared helped one patient gain access to his true suffering. I was making an initial visit to a patient, a man in his 70s from a community about 60 miles away. His shades were drawn and he was blankly watching TV. I sensed something catastrophic had happened. He volunteered, "I have terminal cancer." I asked him if he wanted to talk about it. He said he could not. I took a seat by his bed and waited in silence. Slowly out came his story. The physician had come in several hours before and told him he had terminal cancer. No one was with him when he heard the news. No one visited. No one called pastoral care. His deepest suffering was not his cancer *per se*, but how this would affect his ability to care for his wife crippled with severe arthritis. The words and tears poured out until there were no more. I could find no words, just presence and a comforting hand on his arm. The shades were up when I made my next visit. The patient had talked to his wife and together they had begun to discuss possible alternatives.

"To get to my body, my physician has to get to my character."

Several interviews with doctors underscore the importance of story for exemplary patient/physician relationships:

> Internal medicine is the oldest specialty of medicine. It focuses on the whole person and that's why I chose it.
>
> I chose a smaller community to practice in so that I could practice with a more personal touch.
>
> Listening to stories helps patients and helps me get to know them better as persons.
>
> I grow and I learn from the stories of patients. I tell patients I don't know how it feels to have cancer and would they please tell me.
>
> Lack of time is the biggest obstacle in attending to my patients' stories.
>
> There is a sense of honesty for me when I have really been with a patient mentally as well as physically. So much of my practice is routine procedures. Entering into a patient's story is what makes my work worthwhile. It's the creative part of my work. It's knowing you have a trusted relationship with a patient when you can sit down and talk about depression and its chronic effect on his health.
>
> While there is a push for medicine to be more person-oriented, government limitations, bureaucracy, hordes of paper work and the legal climate are obstacles we work with every day. They war against the quality of medicine I want to practice.
>
> This old codger was regarded as a mean buzzard, non-compliant with his medicines. He had been shuffled from physician to physician. When I got him I decided to take time to get to know him, to show an interest in him.

He has stuck with me and now takes his medicine and is sick less often.

I depend on the nurses and social workers to help me round out what is going on with the patient.

I hope that medicine will become more person oriented because more women are becoming physicians. I believe we bring more empathy and vulnerability to our practices and are able to show it more easily to our patients.[12]

Physicians need to tell their own stories as a way of explaining what gives meaning to their practice, how their professional and personal needs can be satisfied, why they sometimes feel frustrated. Who will listen? Improved relationships will develop as patients reflect about the role of health care (especially high technology) in their lives, and as physicians grow more attuned to stories of sickness.

Physicians need to tell their own stories to explain what gives meaning to their practice.

Encouraging patients to tell their stories has been the crux of my work as a hospital chaplain. This approach respects the patient and thereby assures better visits. Patients come alive emotionally and physically, often forgetting pain and fatigue. Everyone on the health care team should listen with a third ear: What do you enjoy doing? It sounds like you really try to live by your values—did someone you know live the same way? How did you two meet? Do you have a special memory from childhood? What does this illness mean to you? How will it change your life—or your life together? Will other people be affected?

We are just now beginning to question, much less fathom, how and why we heal. Bill Moyers, in his 1993 television series *Healing and the Mind*, showed why narrative is vital by telling stories about the connection between mind and body and pointing out what goes wrong when this connection goes awry. As the various health care disciplines acknowledge the importance of patients' stories, they will recover Osler's model of medicine—and this will be healthy for both patients and professionals.

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