

Whole Person Care

Transforming
Healthcare

Tom A. Hutchinson



Springer

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*For June and for
Kate, Clare, and Nora*

Preface

This book comes out of a deep appreciation of medicine, all that it is and all that it can be in the future. For me working in healthcare has been a love affair. And like all love affairs, it has had its moments of distance, difficulty, and even suffering. The aim of the book is not to avoid the suffering but to make medicine and healthcare even more uniquely satisfying for those who practice it, whether as physicians, nurses, or other healthcare professionals. The primary beneficiaries of whole person care will be patients. It is a win-win proposition.

The book is written in two sections and 18 chapters, and, although the individual chapters also stand on their own, this book is meant to be read from start to finish, as you would read a novel. I hope that you enjoy it.

Montreal, QC, Canada
February 23, 2017

Dr. Tom A. Hutchinson

Introductory

“I go to encounter for the millionth time the reality of experience and to forge in the smithy of my soul the uncreated conscience of my race.”

James Joyce, 1914

*“We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.”*

T.S. Eliot, 1942

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This book grew out of the dynamic and nurturing environment of the Faculty of Medicine at McGill University over the past two decades. To learn more about that environment and the people involved, please see the acknowledgment section of our previous book on whole person care.¹ I would like to reiterate my thanks to all of those people. I want to thank particularly Dr. Balfour Mount and Dr. Michael Kearney who are the originators of whole person care at McGill. Without Bal, and Michael the writing of this book would not have been possible.

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Part I
Whole Person Care: Vision

Chapter 1

A New Vision for Healthcare

*“Or, take a surgical operation.
In consultation with the doctor and the surgeon,
In going to bed in the nursing home,
In talking to the matron, you are still the subject,
The centre of reality. But, stretched on the table,
You are a piece of furniture in a repair shop.
For those who surround you, the masked actors;
All there is of you is your body.
And the ‘you’ is withdrawn.”*

Eliot, TS. The cocktail party

Do Not Go Gentle

When my wife and I were in our early 20s, she developed sarcoidosis. It was the acute kind with hilar lymph nodes and erythema nodosum. That seemed to be the diagnosis, but I was a medical resident and as much as I wanted to believe this was an acute episode that would resolve, she and I both feared this might not be so. To me those lymph nodes on her chest X-ray looked very threatening. Could this be a lymphoma? And if it was sarcoidosis, how would it resolve? Were we facing a chronic illness?

I was not a stranger to the diagnosis of sarcoidosis. I myself had been diagnosed with possible sarcoidosis when I was 14. I remember that time very vividly: opening an envelope that I was to give to a radiologist and seeing the word sarcoidosis with a question mark and going to the library to find out that this disease could involve many organs—the lungs, the joints, the skin, and the heart. The 5-year mortality was quoted at 5–10%. It was terrifying. But what I remember best was leaving the doctor’s office on a rainy dull Irish winter day with a prescription for pills. I looked at people passing me by and thought “They are normal” and “I have joined the ranks of the sick.” I had a dull feeling in my abdomen, my life was over.

Perhaps it was that feeling that made me do what I did when I visited June on a Sunday afternoon in her room at the hospital. There weren't too many people around. I closed the door quietly and unpacked the treats I planned to share with June. I took out two sherry glasses and a bottle of sherry. June and I sipped the sherry and lit up some small Dutch cigars that we favored at that time, and we smoked and drank for an hour or so. We certainly felt better but is this the recommended treatment for sarcoidosis or any other disease? Well of course not, but was it the right treatment for the people that we were then?

What were we trying to do with this flagrant disregard for hospital rules and engagement in behavior that no doctor would recommend? We were making a statement I believe that June would "not go gentle into that good night" [1]. It is the same night with which I had been threatened at age 14. Whatever happened she was not going to become just a patient. We would continue to live what for us then represented the good life. And in over 40 years of practice, I have never met a person, however sick, who did not want to preserve a precious part of their very individual lives that had nothing to do with being a patient.

I remember a man who came to the emergency room with terminal AIDS. He was cachectic and had weeks to live. We talked and at one point he said to me, "You are the kind of man I would like to have a drink with." I asked him, "Well, if we were drinking, what would you drink?" "Irish coffee," he said. The next day I went to see him on the palliative care ward with a bottle of Irish whiskey, cream, coffee, and Irish coffee glasses. I went through the ritual of making an Irish coffee, and we sat and drank our Irish coffees and chatted. He appeared amazed and delighted.

Do I recommend cigar smoke, sherry, whiskey, or other potentially harmful substances in combating sarcoidosis, AIDS, or any other disease? No. But we are asking too small a question. The larger question is whether there is room in medicine for the underlying drive that led to the behaviors I describe, to respect (and even love?) people for their unique characteristics, wishes, and longings that they bring with them into medical care and to see this uniqueness as a source of strength and energy that needs to be tapped in maximizing quality of life. This is the question posed by whole person care and is the subject of this book.

Personal Origins

The origin of whole person care comes primarily from the work of Michael Kearney [2] and Balfour Mount [3], but in my own case, there was a different initiation, the work of pioneering family therapist, Virginia Satir. In the early 1980s, I was a staff nephrologist, heavily involved in patient care

and research. A colleague of mine suggested that I attend a 4-day workshop by Virginia Satir, a famous family therapist. My wife, June, and I attended. I primarily went because I trusted my colleague but did not know what to expect. I was surprised. At first I was confused and somewhat appalled. Virginia conducted a very interactive session, asking people up to join her on stage in role-plays and talking in a way that did not fit any theory of which I was aware. Was she a Freudian or a Jungian (with both of whose work I was very superficially acquainted), or was she flying by the seat of her pants? I remember one gentleman who was having difficulty in his relationships. At some point Virginia called for ropes. She began to tie the man up. There was a rope on one arm to his wife, another from a leg to a son, around his neck to his mother, and so on. She asked him did this feel familiar. He said yes. How did he feel? Well, pretty constricted. She began to remove the ropes at which point I became angry. Didn't she realize how important these connections were? The woman was not only incoherent, but also she was dangerous. And yet I began to sense a feeling of possibility and hope. Was I also tied up with ropes of expectations to my work, my wife, my parents, and even the kids I hoped to have?

As the workshop progressed, I felt more alive and more scared. I was scared because there were repeated role-plays, and I was terrified to be asked to play a part. This happened on the second day when I was asked to play the role of the cartoonist Gary Larson, of whom I had never heard. How could I do this? And yet I did, with help, and reasonably successfully. From that point on, I became more and more intrigued and energized. By the end of the workshop, I said to June, "We have got to make space for this in our lives." And I have attempted to do so, both in my personal life and in my work.

Initiating Healing

The stories at the start of this chapter are the initiation of the healing process [4], which begins with getting people in touch with what gives their life energy, hope, and a sense of their own unique loves and likes, wherever they are in their lives. Too often in medicine, we trample on those delicate and precious preferences, loves, and longings. The healing process never gets started. I believe that if someone had rushed into my wife's room on that Sunday afternoon and berated us for breaking the rules and threatened to ban me from visiting, something like that would have resulted—more wounding rather than a beginning of healing. If I had dismissed out of hand my patient's wish to drink with me, I believe the result would have been the same. I believe we do that all the time in medicine, usually unintentionally.

To deal with illness, or indeed life, we may need the sense of our own value as persons supported and enhanced. That is what Virginia Satir did so well. Whatever doubts I had at the beginning of her workshop, she radiated such warmth and projected such interest and confidence in us as individuals that it became easier and easier to listen to her call. Nothing was pathologized, and everything was considered potentially useful and valuable. One phrase that she used was that people were not scarred by life, they were textured by living. Suddenly my problematic background changed from a wound from which I might never fully recover to a texturing that could give me unique resources to deal with life.

Separating the Patient from the Disease

Separating the person from the diagnosis has therapeutic value that is unrelated to whether we can cure the disease. I recall a patient who was dying of metastatic pancreatic cancer. He was a charming go-getter in his 50s, a successful real estate agent, and a runner. He had noticed while running that he began to have pain in his thighs and hips. He went to see his family doctor who prescribed NSAIDs and told him to keep running. The pain persisted, and he went back to his doctor and the NSAIDs were changed. The pain got worse and finally he ended up seeing an orthopedic surgeon who did a CT scan and found multiple metastases of the pancreatic cancer that was now killing him. What was his reaction when he heard the diagnosis? He was relieved. This was not something he was imagining, it was not a problem with him as a person, it was a disease that he had. Medicine has been separating the disease from the person for thousands of years, and the recent history of this process is well described by Aronowitz [5]. It is a crucial part of our role that is underlined by the suffering of patients whose diseases are unvalidated or only partly validated. There are a number of effects of this validation. First, it may provide an opening for effective therapy. But even if it does not do this, it opens the way for growth and development of the healthy person with a disease, as opposed to a diseased person.

Bill Wilson and the Story of Alcoholics Anonymous

Bill Wilson was an intelligent and, at times, successful businessman whose life was severely affected by a serious problem. In the terms used at the time, he was a lush and a drunk. He ended up being the leader of the most successful social movement of the twentieth century. How did this happen?

As well portrayed in the play by Samuel Shem and Janet Surrey [6], he met Dr. Bob Smith, a GP in Akron, Ohio, who was also a drunk. Bill had the insight that what drunks needed was to help other drunks, the only people who could understand their problem. Dr. Bob's contribution was to evoke the power of medical diagnosis. Drunks were not morally weak, psychologically defective, or lacking will power. They had a medical problem that was subsequently named alcoholism. It turned out that this disease could not be cured, but Alcoholics Anonymous empowered alcoholics to use the healthy part of themselves to support each other in a process of growth and development that came to be called recovery.

Implications for Practice

What implications does this separation of the disease from the person have for medical practice? First, it validates the whole growth and development of Western medicine that uses scientific understanding to provide a more precise delineation and characterization of disease processes. We can now name with authority, clarity, and often precise causal understanding diseases that in the past were nebulous and mysterious. Pulmonary phthisis turned a long time ago into tuberculosis, a disease caused by the tubercle bacillus. Peptic ulcer, a disease previously attributed to stress, is now understood to be caused by *Helicobacter pylori*. AIDS is not a plague of God on a lifestyle but a virus infection, and so on. The more we understand, the more we can relieve patients of the sense that there is something wrong with them. Now they have a disease which we can help them to deal with.

There is a second implication. Our job as physicians is more complicated than we might have expected. We might assume that our job is simply to diagnose and treat disease. But what about the person of the patient that we have now separated from the disease? We have a second and equally important job—the facilitation of healing in response to illness. This is the process that we mentioned previously in relation to Balfour Mount and Michael Kearney and to Virginia Satir. Are we responsible for both curing and fixing what can be fixed and for the facilitation of healing? Yes! That is the message of whole person care. It sounds challenging, but it has great rewards for both the patient and the healthcare practitioner. I believe it is the reason that most of us got into medicine in the first place. Rather than describe it further, let me give you an example from my own practice.

Grace Under Pressure

I met Mr. K on the surgical ward of the Royal Victoria Hospital. He had been admitted to the vascular service because of a catastrophic complication of lung cancer. He had a severe hypercoagulability and was clotting not just veins but arteries. He had clotted the arteries to his legs and feet with the result that his feet were turning black and gangrenous with excruciating pain. I was asked to see him as part of the palliative care team primarily to control his pain. I saw him over a period of 3 months and attempted to treat his symptoms and support him in what was clearly a difficult and harrowing period for him and his partner.

When I first saw him, he was clearly suffering although he had a tough guy feel about him that I really liked and admired. We started him on methadone for his “neuropathic” pain, and with much adjustment and addition and subtraction of other pain medications, we managed to control his pain reasonably well, although he had alarmingly frequent but just manageable periods of opioid toxicity and hallucinations. Controlling his pain was a crucial first step because although pain is not suffering it certainly causes it, particularly if there is no expectation of quick relief or association with something very positive in one’s life. The associations here were all negative.

The next step was that oncology came to see him and decided that no chemotherapy was feasible. He was faced with an incurable cancer accompanied by a severe complication and a life expectancy of months. It was not possible for him to go home as he was on full-dose heparin that needed to be monitored daily. A trial discharge with subcutaneous heparin had been tried, but he was back in a day or so with rapidly progressing signs of further ischemia. He needed to be in hospital on heparin for the foreseeable future and probably till he died.

We saw him daily, primarily to control his pain, but gradually we became more and more important in his case. The vascular service, while tolerant and understanding, did not feel he was primarily a vascular patient (no intervention or surgery possible), and oncology, while they visited occasionally, felt there was nothing more for them to do. We explored admitting him to the palliative care ward, but they could not handle full-dose heparin, and while there might have been a way around this problem, his wife visited the unit and found it too quiet and shadowed by death.

As we came to visit daily, we realized that he and his wife expected and looked forward to our visits. On a few occasions, we came at times when his wife was not there, and she expressed distress that she had missed us. We began to visit at roughly the same time every morning. We would sit down and spend roughly 20 minutes. Those visits were our attempt to care for him and facilitate healing.

The visits usually had three components. First, we explored his symptoms and made decisions about adjustments to his medications. For this part we were primarily in charge and he was the patient. Second, we often had to discuss where he went next. This involved possible transfer to the palliative care unit as mentioned above and also dealing with pressure from the surgical/vascular service to transfer him somewhere else. For this second part, we were primarily advocates for the patient, either speaking directly to the relevant service or instructing the patient how to resist the system—"don't agree to move whatever they tell you!" The resistance worked and he stayed on the surgical ward. The third part would not have happened without the first two, but was perhaps the most interesting and healing. We got to know him and his wife as people. They were delightful. She was Mohawk and he was Russian. He wanted us to hear stories about his earlier life in Russia. He had been a restless young man wanting to leave the USSR before it had broken up. He made an attempt over land (and water I think) which was unsuccessful and then decided to take a more radical approach. He and some friends bought a gun and made plans to hijack a commercial aircraft. The KGB rounded up the group before they could make good on their plans. Mr. K was shipped off to Siberia for 7 years. That was where he received his education—from other prisoners.

There were other stories and perhaps the content is less important than that he wanted us to hear them and know him, and we were interested and even riveted. I did wonder if his education in Siberia prepared him for the rigors of his disease and a room on the surgical ward for many months. However, it was not primarily what we heard but that we took the time, were genuinely interested, and came to see him as the fascinating and resourceful person that he was. Did I become his friend? No, but within the context of the medical system, I came to relate to him, person to person. I believe there was something in my Irish attitude to life that made it easy to relate to this Russian man. I tried to put myself in his shoes and realized what an amazing job he was doing in dealing with his illness. I could not imagine coming even close to his ability to be so alive and together if the roles were reversed. The closest I can get to the experience is when I was in school and we had lessons from the great West Indian cricketer, Frank Worrell. He was at a level and could do things I could not even imagine. Watching Mr. K was like that. He may have picked up my esteem and admiration for him. I hope that he did. And yet I knew I was also contributing something important.

The result, and not primarily of our support but of what he and his wife were able to find in themselves, was a healing journey. They became closer. She said that they had always gotten on well but now their relationship was deeper. At some point they decided to get married, and we attended the wedding in his room on the surgical ward. Their influence spread out from their

room so that more and more of the surgical nurses became concerned about contributing to Mr. K's care. Mr. K died when I was on a trip to Japan. I met Mrs. K and her sister afterwards with other members of the team, and they brought gifts, including a beautiful Mohawk-feathered instrument for the smudging ceremony. Mrs. K said, "This is for your group because it represents healing and that is what you do."

Conclusions

To return to the story at the beginning of this chapter, what my wife and I most feared when she developed sarcoidosis was that she would lose herself as a person. That was also what I feared when I was 14. I believe it is at the heart of what every patient fears when they become ill. Will I still be the person I know as this disease takes its toll? What whole person care stands for is that while we will do everything possible to fix what can be fixed, we will also foster a caring relationship with patients as the unique and valuable whole people that they are now and be ready to support them in the journey of healing that may be necessary as they learn how to live with their illness. We will explore in later chapters the mechanisms for and implications of this task for medical practice, but first we need to look at the history of medicine to explain how we have come to be increasingly distanced from this crucial part of our mission.

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Chapter 2

A Brief Recapitulation of Medical History in Six Movements

“Mankind are so much the same, in all times and places, that history informs us of nothing new or strange in this particular. Its chief use is only to discover the constant and universal principles of human nature.”

David Hume

Shamanism

In the 1990s I attended a 4-day workshop led by Michael Harner, the leading exponent of shamanism then teaching in North America [1]. The workshop began badly for me because I lost my stone. This was a roughly grapefruit-sized rock that we were asked to bring with us. Somewhere between leaving Montreal and the morning of the first workshop in New York State, my stone disappeared. I was appalled. When I told Michael Harner, a lively man with a mustache in his 50s, he laughed. I realized I was being perhaps a little obsessive about this workshop. I guess you might say I was stuck in a very ordinary reality while attending a workshop specifically aimed at exploring non-ordinary reality.

Perhaps for that reason, the workshop had very little power for me. I seemed to be asked to believe things that stretched my understanding too far. One of these had to do with the meaning of some of the marks on my stone (I had found a replacement). I could not bring myself to believe that what looked like random markings carried a deeper meaning. I remember at one point we danced to the sound of a drum and Michael picked out one person as really in a trance. I was annoyed that I had not made the grade. I also thought the person that he had picked was acting in an unnecessarily silly way. I left the workshop after 4 days with a drumming tape and a resolve to master this phenomenon. I did the required meditations with the drumming beating in my ears and tried to imagine myself descending into the underworld. I could not get myself to believe a word of it. Perhaps the cultural/historical gap was too large for me to bridge.

And yet shamanism is, I believe, the prehistorical origin of medical practice. I have subsequently read further on the topic and had further experience with both a First Nations Grand Chief who was an expert in the healing of her people, and with an Algonquin medicine man. Here is what I have learned:

- Separation of patient and disease is an intrinsic part of ancient shamanic practice. There are various ways this is expressed. Sometimes the shaman sucks out a power that has intruded into the patient, and sometimes he actually sucks out (or appears to) a physical object that is identified as the cause of the problem [2]. At other times and in some cultures, the shaman identifies the cause of the illness as an invasion by a person or evil spirit (possibly from another tribe) and directs his energy against the intrusive being. The basic belief is that the patients themselves are healthy, that disease is not natural to them, and what is required for cure is to remove or eradicate a foreign intruder. This is exactly analogous to our twenty-first-century conception of separating the disease from the person.
- In addition to dealing with the disease, the shaman's other job is to increase the power of the basically healthy person that is the patient. This can take many forms that people within a particular culture would consider literally true. The shaman might travel to the underworld to retrieve the patient's soul [3, p. 72]. This has an analogy in twenty-first-century medicine. When I became sick at the age of 14, I was afraid of losing myself (my soul?). I needed some reassurance that this would not happen or, if it was beginning to happen, that I could be retrieved. The shaman might also put the patient back in contact with a power animal [4]. This was a part of shamanism that had no resonance for me. And yet when people are sick, they do want to get in touch with a talisman of their personal and cultural power. Is that what these animals represent? Is that why Mr. K told me stories of his rebellious youth and experience in Siberia? Was he getting back in touch with an experience of personal power that he needed to remind himself was still available to him?
- The shaman is the original wounded healer [5, p. 45]. In different cultures it happens in different ways but in all of them there is some version of illness, death, and resurrection in the formation of a shaman. This can be a spontaneous illness (either physical, psychological, or both) or an initiation experience that mimics illness. This seems to require the shaman to have a near-death experience in which his survival is by no means certain. In the case of Igjugarjuk, an Inuit initiate, he was left without food for 30 days in a small snow hut [6, p. 65]. He received sips of warm water twice during that period while he awaited his spirit helper. As he describes it, he faced suffering and possible death through the two things that appeared to him the most threatening to human beings—hunger and cold. His spirit helper did come in a dream and he did survive to become a shaman. The shaman becomes a shaman not just because he becomes ill or suffers severely, but because he gets in touch with something that allows him to get through the experience. Both parts are necessary. As

Michael Kearney has pointed out, relating as a wounded healer is the key element in facilitating healing [7]. As a wounded healer, I relate to you as brother. You are sick now but I may be just as sick one day. In the shaman's case, even more powerfully, I have been sick like you in the past and can directly relate to your experience out of my own. Further, since I found a way through, I represent what is possible for you. This I believe is the deepest and most crucial part of shamanic practice.

- If removal of the intrusion that caused the illness is taken as curing, and the enhancement of personal power is taken as healing, then the shaman embodies both in one person. This probably remained the case for many thousands of years in what were hunting gathering cultures. As our ways of life began to change, and with them our cultural organization, these two functions became separated, as illustrated by the organization of medicine in classical Greece.

Ancient Greece: The Separation of Curing from Healing

I love Karen Armstrong's clear explanation of the ancient Greek distinction between *logos* and *mythos* [8]. *Logos* is the language and thinking of our everyday lives—concrete, logical, and practical. *Mythos* is the language of meaning and dreams and myth—not tied to concrete concepts and things, not necessarily logical, and not practical, but very important. She makes the case that the Greeks would never confuse these two. Certainly, as far as medical care is concerned, they appear to have kept this distinction very clear.

According to Michael Kearney, when an ancient Greek patient became sick, he looked for help from two sources [9]. First, he visited a temple to Asklepios, the god of healing. In the temple he participated in ritual and ceremonies of healing with the priests and then slept in a part of the temple designated for that purpose, the *abaton*. There he awaited a dream or visitation from Asklepios. The next day he reported his dream. The dream was the initiation of healing. In Kearney's terms, it is a move towards a sense of wholeness that comes from within the patient.

The second source of help came from practitioners like Hippocrates who plied their trade on the outskirts of the temple. They met patients arriving and leaving, attempting to fix what could be fixed. While the ceremonies in the temple were clearly in the realm of *mythos*, Hippocrates was firmly in the world of *logos*. He made observations, came up with theories and explanations, and prescribed treatment. His followers developed a code of ethical behavior that is still a basis for oaths taken by medical practitioners.

The Greek god of healing has strong links to shamanism. Asklepios was the child of a human mother and of the god Apollo. His mother died in childbirth



Fig. 2.1 Chiron, the wounded healer. From: Heidelberger historische Bestände - digital: Archäologische Literatur Universitätsbibliothek Heidelberg

and he was raised by Chiron (Fig. 2.1). It was from Chiron that he learned healing. Chiron is an almost perfect link to and reenactment of the shamanic journey. First, as shown in the diagram, he is clearly a hunter with a hunting dog and carrying game that he has captured in the hunt, the Greek link to the hunting/gathering culture that they had left behind. He also embodies animal powers. He is a centaur, half man and half horse. And as Kearney points out, he is a wounded healer [7, p. 98]. It turns out that when he was at a party with other centaurs he suffered a wound from an arrow in his knee. The wound never healed. Out of his woundedness, he became a healer for others. At one point in his life, he undertook an even more dangerous and profound healing journey on behalf of another person. Here is Kearney's description [5, p. 46]: "One day Hercules returned, bringing news that if Chiron was willing to sacrifice his immortality on behalf of Prometheus, who was being punished for mocking the Gods, he too could be freed of his suffering. Chiron agreed to this; he died and descended to the underworld. For nine days and nine nights he remained in the darkness of death. Then Zeus, recognizing the generosity of this sacrifice, took pity on Chiron and restored his immortality, raising him to the heavens as a constellation of stars."

But neither Chiron nor his adopted son Asklepios were life and blood shamans embodying in one person the experience of illness and healing and the power to separate the patient from the intrusion of disease. In the brilliant Greek separation of ideas and modes of thinking, these functions had

been delegated to different professions. The priests in the temple did not necessarily bring their own experience of illness and healing to the patient but were masters of a ceremony that evoked the presence of gods who represented this experience. Hippocrates and his colleagues had taken on the function of separating the patient from the disease and dealing with this intrusion into the patient's body. They were firmly in the world of logos and left mythos to the priests in the temple.

The Twentieth Century: Focus on Biology of Disease

We have taken the Hippocratic approach quite a long way in the last 2500 years with beneficial effects on our understanding of disease and biologic processes. As a medical student in the 1960s, I saw some of the results of this growth first hand. I was particularly attracted to nephrology and an understanding of acid-base and electrolyte balance in which the diagnostic process could be so clear and precise.

I remember one evening just before I was to leave the hospital the registrar showed me a set of blood results from a man who had been admitted that day with a probable lung cancer. The patient had a severe metabolic alkalosis and hypokalemia. The registrar asked, "What do you think is going on?" I said I thought that this was a mineralocorticoid effect of secreting huge amounts of cortisol that resulted from an ACTH-secreting tumor of the lung. I was subsequently proved correct. This was an example to me of an interesting and satisfying case that I planned to write up.

In my internship, residency training, and practice as a nephrologist, I saw this growth of knowledge and interest in the biology of disease at close quarters. The process gradually moved away from the bedside to the laboratory and away from the study of whole patients to whole organs, to cells, and to subcellular particles [10]. By the time I finished my career as a nephrologist, presentations on research were almost exclusively focused on molecular biology and almost never mentioned the kidney, never mind the patient. The process that Hippocrates had started had gone very far indeed.

Evidence-Based Medicine

But I discovered that there were other strands in medical research. Through a mentor during residency, I got in touch with the work of Alvan Feinstein and read his book *Clinical Judgement* [11]. Alvan Feinstein was a clinically sophisticated and mathematically astute thinker who realized that patients'

symptoms could tell us a lot about disease behavior. He began his work with prognostic insights in rheumatic fever, but he devoted most of his work to understanding the behavior and management of different cancers. He showed, for instance, that what symptoms a patient had and for how long told us about the rate of growth of the tumor and had implications for screening, prognosis, and appropriate treatment for common cancers such as lung and breast. He opened up the whole new field of clinical epidemiology. I joined Dr. Feinstein for 2 years of training at Yale and pursued my career as a nephrologist and clinical epidemiologic researcher. Clinical epidemiology morphed into evidence-based medicine [12] that so dominates our thinking and practice of healthcare today.

What clinical epidemiology and subsequently evidence-based practice have done is to use data from patients to assess diagnosis, prognosis, and treatment. These disciplines have developed rigorous methods for evaluating and measuring subjective symptoms of patients, for predicting outcomes, and for assessing the efficacy of treatments. Randomized trials have become the gold standard of evidence-based research. This focus of research has brought us closer to the patient but with one crucial omission. In Feinstein's words, "The personal environmental management of a patient is a challenge to the clinician's judgement as a humanistic healing" [13, p. 29–30] which is not dealt with in *Clinical Judgement* or subsequent developments in this field.

Why is this so? I believe it is because this personal and potentially healing relationship with the patient calls on a different part of our being and thinking that the shaman would have identified as the journey to another sphere and the Greeks would have transferred to the temple. And yet I don't believe it has to be so extreme or dramatic. Take for instance the patient discussed earlier. Having been diagnosed with an ACTH-secreting lung tumor, what help did he need? He did receive an experimental drug for endocrine-secreting tumors for which evidence-based assessment would have been appropriate. The treatment did not work; the patient stayed on the ward with follow-up investigations, deteriorated, and died over a period of weeks. During that time no one discussed his disease with him or acknowledged its severity. His family was informed but the approach at that time was to protect the patient. The result was a man dying in effective isolation. The picture I retain is of a somewhat flushed man in his fifties sitting up in bed, and smiling, and looking frightened. It was evident to me as a student that we were missing something crucial although I had no idea what to do about it. He was clearly suffering, but what in our medical armamentarium would help? To answer that question, we need to look at a parallel development in medical care that also started in 1967, the same year that Feinstein's book was published.

Palliative Care: Bringing the Two Sides Together

In 1967 Cicely Saunders opened St. Christopher's Hospice in East London and started the modern hospice and palliative care movement [14, p. 127]. She had been a nurse, and then a social worker, and finally became a medical doctor to revolutionize the care of the dying [15]. She had been deeply affected by the death of a young Polish patient under her care and had seen in St. Joseph's Hospice a kind of caring that patients who were seriously ill and dying urgently needed. St. Joseph's was run by the Irish Sisters of Charity and was a continuation of a long tradition going back to medieval times of hospitals and hospices run by religious institutions. Dr. Saunders realized that this was a crucial part of what patients needed, but they also needed the most scientifically based and evidence-supported treatment that medicine could provide. She founded St. Christopher's to reunite these two parts of medicine. In Greek terms she was bringing together logos and mythos in one institution. There is no question that her experiment has been a resounding success with over 8000 hospices and palliative care units spread across all parts of the world.

I spent 2 weeks in St. Christopher's in 2002. I got a sense of the institution, made rounds with the attending physicians, and saw both the level of rigorous evidenced-based care and, in Feinstein's terms, the level of humanistic healing care that was provided. It was exactly what my patient in Ireland would have needed. I also saw that humanistic care did not have to be dramatic, religiously framed, or culturally challenging. As Balfour Mount has shown, what is needed for healing is connection [16]. It may be that for hunting/gathering societies that connection is best framed as contacting animal powers or journeys to another realm of meaning. For the ancient Greeks, connection may have been created by dreaming in a temple dedicated to Asklepios. For most of us and our patients, these particular vehicles of meaning and connection may have no resonance. But our patients do need connection, often in the most ordinary kinds of ways. I saw this acted out on a moment-to-moment basis at St. Christopher's in how the doctors spoke with and listened to their patients, in the discussions between doctors and nurses about what a particular patient needed today, and in the welcoming and caring culture that permeated every aspect of the institution.

My most direct and personal experience of the power of the connectedness that they were promoting came when I participated in the day hospital. Up to that point, I had been an observer, but one of the staff physicians suggested that I might like to participate in the day hospital as if I was a patient. This was not like the usual day hospital with which I was familiar. This was

like a home away from home in which interesting activities were provided for patients, some of whom visited from home for the day and others from their hospital beds.

When I arrived at the day hospital, we were welcomed and paired up. My partner was a very thin woman from the Caribbean who looked very sick indeed. In the morning we iced a cake. We were given instructions and free rein in this creative activity at which neither of us was expert. The morning flew as we laughed and bonded in this activity that was, I believe, both challenging and strangely familiar to both of us. I wondered if it echoed similar activities from our childhoods. By the end of the morning, we were engaging each other in a kind of intimate connection that for me at least was completely unexpected. At lunch time our orders were taken, including our drinks orders. I could hardly believe it when people ordered gins and tonics, beer, sherry, and so on. This was not like a medical day hospital or clinic. This was people being treated like normal adult human beings. And I believe that is the point. What illness can rob us of is the sense of normality, the connection with the person we have known ourselves to be before we became ill. The healing journey may involve change, but it also involves honoring the person we bring into that journey. Is this perhaps the twenty-first-century version of retrieving our lost souls—a reaffirmation that no matter how sick, we have not lost ourselves. Who we are still matters and still counts. In Cicely Saunders' words, "You matter because you are you."

In the afternoon we dyed a scarf together, and the next day I had lunch with Cicely Saunders who wished me bon voyage. I returned to Montreal to practice palliative care and collaborate with Balfour Mount in developing McGill Programs in Whole Person Care. What Cicely Saunders achieved in bringing together curing and healing is not just relevant for dying patients but for all patients, which is the message of whole person care. Healing a split that has been present for thousands of years sounds like quite a challenge, and yet we believe that it is both feasible and necessary.

The Twenty-First Century: Whole Person Care

The pivotal year was 1999. Having founded and developed the first palliative care unit in North America, Dr. Balfour Mount was planning to leave McGill to set up a program with wider implications for medicine at another institution. As he described it to me, he met with the Dean of Medicine, Abraham Fuks, who asked, "Why not set up the program you want here?" Bal started McGill Programs in Whole Person Care that aimed at reincorporating healing into the medical mandate. He set up a Faculty Working Group

on Healing to develop a formal proposal for Dean Fuks on how this could be achieved. The working group involved physicians from many departments and divisions and included Michael Kearney as a visiting professor. The group met over a 2-year period.

Both Michael Kearney and Balfour Mount had worked at St. Christopher's Hospice with Cicely Saunders. Michael Kearney had gone there first as a disillusioned medical student. He subsequently became a consultant physician at St. Christopher's. Balfour Mount had visited St. Christopher's in the 1970s and had taken what he learned there to set up a palliative care unit at the Royal Victoria Hospital in Montreal. Both Kearney and Mount realized that what they saw at St. Christopher's had implications far outside the needs of dying patients. The key insight was an almost complete disconnection between the level of disease and the subjective quality of life in some of their dying patients. Here is Dr. Mount's description of the paradigmatic case [17]. "CD was 30-years-old when he presented with a widely disseminated germinal testicular cancer. Radical surgery and chemotherapy initially resulted in his tumor markers reverting to negative and the hope of cure, but within months his disease progressed with ensuing extreme cachexia. He died slowly over a 12-month period. CD had always stood out from his peers. He had always been a winner. Strong. Outgoing. Gracious. A world-class athlete, he was a member of the national ski team. He was successful in business and engaged to be married. A champion from a family of competitive champions, he was now melting before the raging forces of the embryonal cell. Then, just days before he died he married his fiancée and said goodbye to those he loved, observing, 'This last year has been the best year of my life'."

Mount and Kearney realized that they were seeing a phenomenon as old as medicine itself, an innate capability of human beings that they called healing. They saw that this capacity to heal was relevant at all stages of disease and needed to be reinstated as a crucial part of the medical mandate. The Faculty Working Group on Healing that Mount set up had exactly that aim. The group reported to Dean Fuks in 2002, the report was accepted, and healing became an integral part of the teaching of medical students at McGill.

The subsequent history is one of the growth and development of the programs at McGill and connections with other groups with similar ideas around the world. At McGill our teaching of medical students is now part of the core curriculum in all 4 years. We published the first book on whole person care in 2011 [18] and held the first International Congress on Whole Person Care in 2013. The basic idea is very simple. When people become ill, they want and need two things: they want whatever can be fixed to be fixed or cured, and they want to continue to be treated as full human beings. It is out of being treated

as full human persons that they are helped to stay in touch with themselves and have the possibility of growing in response to illness, a phenomenon we call healing. And patients need elements of curing and the facilitation of growth and healing from each healthcare practitioner that they encounter. We will explore what this means for medical practice in the chapters that follow.

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Chapter 3

Healing

“You get your priorities straight and all the little things in life don’t matter anymore. Someone once asked me why little things don’t bother me. I told them to have a transplant.”

Brian Ditty

I knew Brian Ditty at a number of points in his life and illness trajectory. Like any patient with renal failure requiring replacement with dialysis and transplantation, he had many ups and downs in his illness experience from times in the ICU when he could have died to a successful kidney transplant that later failed and on and on [1]. He was a delightful and wonderful person who saw the humor in many things and demonstrated wholeness in a very down-to-earth and real way. So I guess you could say that he experienced healing if, as Mount and Kearney assert, healing is a move towards a sense of integrity and wholeness [2]. But it was not a unidirectional journey, more like a roller coaster. This fits with many descriptions of this phenomenon which Michael White would call a migration of identity [3]; Colin Murray-Parkes would see as a psychosocial transition [4]; Virginia Satir would see as the change process [5]; Senge et al. would identify as the Theory of the U [6], which we would call the healing journey [7]; and Joseph Campbell would recognize as the hero’s journey [8]. And Campbell’s terminology is appropriate because there is real heroism in the journeys of people like Brian. We have changed and simplified Campbell’s stages on the journey to fit our experience with patients. It starts with the call.

The Call

In Brian’s case, the call came at the age of 19 when he was told that his kidney function had deteriorated to the point that he needed to start on hemodialysis. He had some warnings in the past, including having an arteriovenous fistula created to allow access for hemodialysis and visiting a hemodialysis

unit with his mother to get a sense of what he was facing. He threw up on the sidewalk right afterwards. But now the time had arrived. He should start hemodialysis right away. And Brian said no!

Refusal of the Call

Brian Ditty's refusal as described in the book "Heroes: 100 Stories of Living with Kidney Disease" [1] was very vehement and clear. He declared that it was not for him, and it was not his lifestyle. When told he would die if he did not start dialysis, he replied that was fine and he had had a good life. It could all have been over there and then for Brian Ditty.

Taking the First Step

Luckily there were others involved. First of all, there was his doctor who expressed in no uncertain terms the urgency to start dialysis. According to Brian, it was his parents who made the difference. We don't know what they said, but it appears that in this case he relinquished the decision making to his parents. They felt he should start dialysis and so he did. In a world in which we place such a high value on patient autonomy, I wonder if there is not a lesson here. To start the healing (hero's) journey, do some of us need to be pushed against our initial preferences to move forward?

Hope

In my experience, the first step on the healing journey often begins without much hope and as in Brian's case often appears to be impelled by circumstances or other people. Whether it is the patient starting dialysis, deciding to begin chemotherapy, or the person agreeing to an operation, the step forward is often made with an overwhelming sense of fear and dread, not knowing what to expect and often expecting the worst. The hope often comes after the first step is taken. Brian went for his first dialysis and met two guys, Ray and Armando, who made fun of the whole thing. They told him, for instance, that now he could drink as much beer as he liked because it was dialyzed out by the machine. It was a crazy nonsensical idea, but it fitted for Brian and made the whole thing fun. I suspect that it gave him hope or more accurately that they, Ray and Armando, as patients who were living the life that he was now started on, embodied the hope that life on

dialysis was possible and could even be enjoyable and include a sense of humor. I believe exactly the same thing happened when my father, Bill, attended his first Alcoholics Anonymous meeting. Did he come back reporting the tenets of AA, enumerating the 12 steps? No! The main thing that gave him hope was that the AA members he met were very well dressed and appeared to be successful—they embodied something he wanted for himself.

The Descent

Regardless of the first step and the sensing of embodied hope which helps to keep people on the healing journey, there is often a descent that sets in after these initial phases. This is not surprising because as Michael White describes it, the process really is a migration of identity [3]. We really are becoming a different person, and there is no way for that to occur without significant suffering. We now have to begin to live this new life and learn to deal with all the changes it brings with it and the threats it poses to our old sense of identity. Why is it important to recognize this phase? Primarily because unless people have some warning, they are likely to believe that they may be doing something wrong. Why else would they be feeling worse now than before they started this journey? I believe it is because of this phase that alcoholics go back to drinking or patients back off the treatment that they have started. This is perhaps the phase at which support is the most important, because hope can be easily lost and the journey aborted before it has reaped the benefits of which it is capable.

The Belly of the Whale

As so vividly implied in Campbell's phrase [8], this is the bottoming out of the healing journey. I believe it is the phase at which the struggle of descent phase turns into acceptance. It is also the phase when we learn about ourselves and our own very individual values. Brian Ditty, for instance, discovered that there was only so much help he could accept from other people. This led him to terminate a personal relationship with a nurse who had been very helpful to him and to decide that he could not live with accepting a living donor kidney from a member of his family—very difficult decisions that fitted with who Brian now felt himself to be. The Belly of the Whale is when we learn more about ourselves, accept our situation, and decide what we will take with us as we move forward.

The Ascent

The ascent is when we begin to forge a new relationship with the world based on our changed identity. We are relating now not as a person waiting for our illness to resolve (so that we can relate in the old way) but as a new kind of person. Perhaps I cannot pursue the career that I had previously envisaged but find that other ways of relating are now more meaningful and important. For patient Andrey Diochon, also with renal failure, he gave up his plan to pursue a career as a policeman and lawyer, and his family became more important to him [9]. The same phenomenon in different guises is expressed repeatedly in the 100 stories of patients with renal failure [10]. For my alcoholic Dad, it manifested as a letting go of complaints about the company that employed him and replaced by an acceptance and gratitude that actually propelled his career forward.

The Return

The ascent implies a return to life, but the added implication of this return phase is that we have something to give back to the world which has nurtured and supported us through the journey. This often takes the form of returning something to people who are experiencing what we went through in the past. For the alcoholic, this might mean sponsoring newer members of AA and for the renal patient helping other patients with the same disease. But there may also be something to give back to the wider world. I would see many works of art in this perspective. James Joyce's *Ulysses* [11], for instance, is a moment-to-moment reenactment of the healing journey in the life of a cuckolded and marginalized man over a single day in Dublin.

Patient Engagement

There has been a recent move to engage patients more actively in healthcare [12]. This has many benefits, but the most important is that, as in Brian Ditty's story or my father's experience with AA, patients can embody for other patients with similar problems the potential for a positive outcome and healing. And as with any healing interaction, the process helps both the person giving and receiving support [13]. As one of our patients on dialysis said "When you provide help to other patients you don't feel like a patient anymore" [14]. It was in an attempt to provide the support from hearing other patients' stories that we produced our book "Heroes: 100 Stories of Living with Kidney Failure" [10] and distributed it

to all 20,000 patients on treatment for renal failure in Canada. However, a person-to-person relationship is probably even more powerful. Part of the incorporation of healing as part of the healthcare mandate and the further development of whole person care will mean providing increasing opportunities for patients to learn and benefit from the experience of others with similar problems.

The Healing Journey

Figure 3.1 shows a diagram of the healing journey from the work of Michael White [3]. The diagram describes the experience of a woman leaving an abusive relationship. As you will see, her experience can easily be fitted to our model of the healing journey. Clearly she has a descent, a low point (Belly of the Whale), and an ascent. Are we to conclude that this is then the blueprint that our patients follow in a predictable and linear way, and our job is to identify this journey in our patients, be clear about what stage they are at, and move them onward to the next phase? Absolutely not! Patients have many different versions of the healing journey and sometimes appear to be going backwards not forwards. And although we play a crucial part in the facilitation of healing, which may occasionally involve pushing, our role is not to oversee or control the journey.

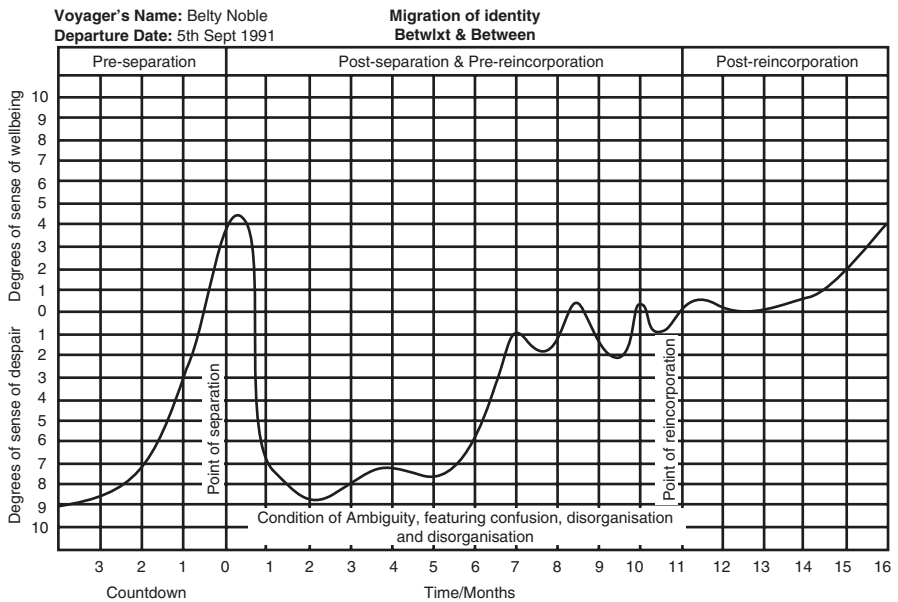


Fig. 3.1 The healing journey in a woman leaving an abusive relationship. From: "Re-Authoring Lives: Interviews & Essays" by Michael White Copyright © 1995 by Dulwich Centre Publications Reprinted by permission of Dulwich Centre Publications

Simple, Complicated, and Complex Problems [15]

Simple problems are like treating an uncomplicated urinary tract infection. Complete the correct prescription and the result will be predictable and reproducible. Complicated problems have been likened to sending a man to the moon. Difficult cardiac surgery or building a new hospital would also be complicated problems. It will take a very detailed blueprint faithfully followed to produce the desired result. Each component element must be successfully completed in the correct order in order to ensure a favorable outcome.

Complex problems are quite different. Raising a child is a good example. Although there may be rough milestones, no two children are alike, and attempts to fit a child into any rigid framework may be harmful and could be disastrous. What then is needed? The key element is establishing a relationship that supports growth and development. The energy for the process and the rate and direction of growth depends on the child. Facilitating healing is very much the same. We need to establish a respectful and supportive relationship. The pace and form of healing will occur in a way that is unique to the individual.

Chaos, Starlings, and Healing

So how does our moment-to-moment caring relationship with patients relate to the overall process of healing with its various phases described above? And since we are not guiding the process and neither are our patients, where does the relatively ordered process of healing arise from? I believe it is an example of the complex order that arises in apparently chaotic systems [16]. In recent decades, this process has been identified as ubiquitous in the natural world from the orderly branching of river systems [17, p. 99–103] to the flocking of birds. If you have ever noticed birds flocking or seen the dramatic videos of huge flocks of starlings flying around Rome [18], you will be aware of the process. Large numbers of birds fly in beautiful and changing patterns with the flock remaining a coherent entity that flies from place to place, avoiding obstacles, as if someone were guiding and leading the process. But there is no leader. In computer simulation, the process can be reproduced by each bird in the flock obeying just three rules: maintain a minimum distance to surrounding birds and other objects in the environment, maintain the same speed as surrounding birds, and attempt to move constantly to the center of the flock [19, p. 41]. I believe this requirement for a particular kind of relationship to allow the unfolding of an orderly complex process in nature is exactly analogous to our role in healing.

The Healthcare Practitioner

What kind of relationship does the facilitation of healing call for from us as physicians or other healthcare practitioners? The main threat that patients face in coming to terms with illness is their sense of loss of their own integrity and value as persons. And it is patient's sense of their value as persons that will be the biggest factor in determining their trajectory on the healing journey. It is very difficult to move forward without a sense of one's own possibilities and value. We can make a difference to that valuation by how we relate to our patients.

Value and Belief

What kind of value or belief system do we need to be able to promote healing? The lower patients are on their own scale of self-value, the more they need validation from us. How do we get in contact with a belief system that supports an unconditional validation of patients as persons, regardless of where they are, or in what direction they are moving on the healing journey? Religions provide a worldview that can certainly supply that need and for those who have a strong religious belief this may be the answer. But what about those who cannot espouse any specific religious belief? Viktor Frankl would say that we are all searching for meaning and that at some level we all do espouse what he would call "ultimate meaning" that is best expressed in love for our fellow man [20]. In whatever way we find that "ultimate meaning" I believe it is an essential part of our job as healthcare practitioners. Otherwise, we will be constantly driven by our likes and dislikes of different patients, which may or may not affect the disease-oriented treatment we offer, but will certainly affect our ability to facilitate healing.

Conclusions

We are not in control of healing, but our relationships with our patients make a major difference to how the process unfolds. Perhaps it is faith in the reality of the healing process and its possibility in individual patients that is the ultimate requirement for an effective healthcare practitioner. We will explore different formulations of the healthcare mandate based on this centrality of relationship and healing to our work in the chapter that follows.

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Chapter 4

The Focus of Medical Care

*“I would go without shirt or shoe
Friend, tobacco or bread,
Sooner than lose for a minute the two
Separate sides to my head!”*

Rudyard Kipling, The Two-Sided Man

We alluded to the separation of the disease from the patient in Chap. 1 as an important step in the relief of suffering and clarifying our different roles in caring for the patient. The resulting three elements in healthcare and their main relationships are pictured in Fig. 4.1. There is the physician (or other healthcare worker), the patient, and the disease, with the relationship of the physician to disease denoted as curing and the relationship of the physician to the patient denoted as healing. Each of these aspects of medical care individually and in different combinations can become the primary focus of medical care.

Physician-Centered Care

At times in the past and even currently, it can appear that physicians are the focus of medical care. The way hospitals are organized, the way clinics are scheduled, and even when, where, how, and whether care is delivered can be primarily dictated by the convenience and life style of physicians. There is data, for instance, that an important determinant of whether different forms of surgery are carried out is the enthusiasm of local surgeons for a particular procedure, not the demographics of the population [1]. Most of us have had the experience of appointment systems that meant long waiting periods. There are many examples of this tendency for physicians to suit themselves, which virtually no one would justify. I believe it is at the heart of a well-established opposing trend towards patient-centered care [2].

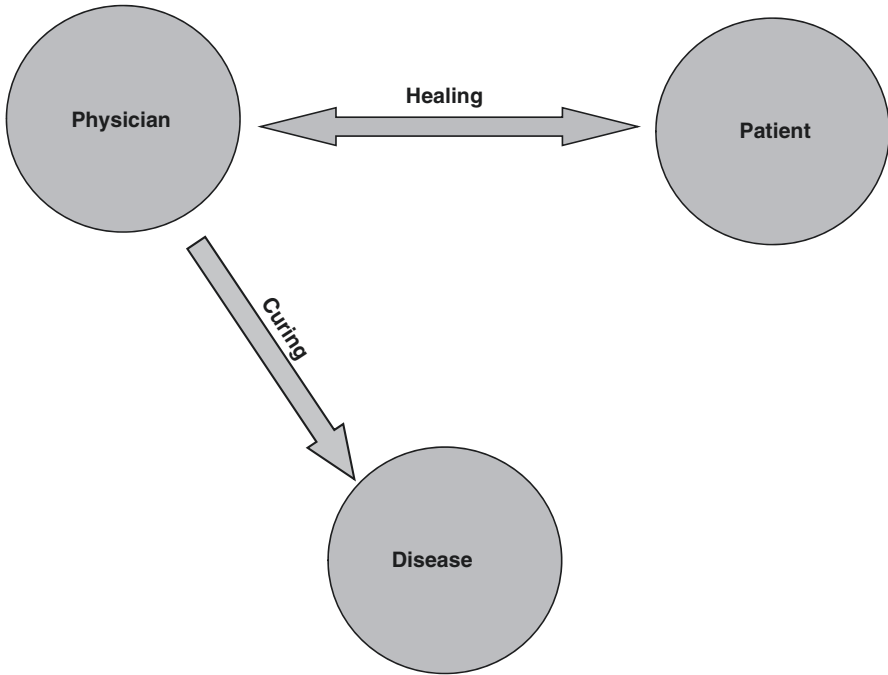


Fig. 4.1 The two therapeutic relationships

Patient-Centered Care

Virtually no one would argue with patient-centered care, which explains its widespread popularity. Obviously the whole purpose of medical care is to help the patient, and everything that we can do to promote this sole objective is to be encouraged. The patient-centered movement has had and will continue to have an important impact on medical care. This has resulted in obvious benefits for patients and their families that include more relaxed visiting hours at hospitals, including intensive care settings, for family and friends to spend time with the patient, increasing attention to the patient's choices and values in deciding on treatment options [3], and a focus on patient satisfaction as an important and measured outcome of medical care [4].

Disease-Centered Care

Since the primary reason that patients come to see a healthcare practitioner is because of a problem that they wish diagnosed and cured, a disease focus of medical care can be very much what patients want. In fact in a

recent trend in medical care with the possibility, or promise, of electronic apps that can diagnose and suggest treatment for a variety of complaints, there is a claim that patient-centered care will in the future leave the physician out of the picture completely [5]. We will have a patient-centered care focused on efficient diagnosis and management of disease through artificial intelligence and expert systems. This may indeed be a future trend but leaves out an important consideration in care—the patient as a person.

Person-Centered Care

The person-centered care movement recognizes that patients are not simply carriers of a disease but unique persons embedded in a complex web of human relationships that affect their response to disease, their suffering, and their healing [6]. The movement calls on us to recognize and acknowledge the full humanity of our patients as only in this way can we care for them as they require. The movement also recognizes that physicians and other care givers are also whole persons whose humanity plays a crucial role in healthcare. The person-centered movement overlaps significantly with another recent movement in healthcare—relationship-centered care.

Relationship-Centered Care

Relationship-centered care puts the primary focus on the relationship between the healthcare worker and the patient [7]. It is not just that the patient counts, or the physician counts, but that both count in a complex human relationship. The term “relationship-centered care” was first used by the Pew-Fetzer Task Force in 1994 which pointed out that the purpose of healthcare is patient centered but the process is necessarily relationship centered [8]. The leading proponent of relationship-centered care is Dr. Anthony Suchman from the University of Rochester. He has published widely on the topic [9] and extended the idea of relationship-centered care to the functioning of healthcare organizations, an approach he calls relationship-centered administration [10]. He and others have played a role in changing the culture of large healthcare institutions and academic centers [11] in the direction of a focus on relationships. Relationship-centered care overlaps considerably with but is not the same as whole person care.

Whole Person Care

As a whole person, what do I want from medical care? First and foremost, I want whatever is wrong with me to be accurately diagnosed and treated. If I have a cough or blood in my urine, I want my physician to identify the cause of that problem and, if possible, eradicate or cure the disease causing it. If that can be done effectively and efficiently by a healthcare worker who takes little notice of me as a person, or even by an app on my iPhone or a robot armed with artificial intelligence, so be it. So my first requirement would be care focused on disease and cure.

However, unless the problem is extremely trivial, I will also require another aspect of care. I will need the person treating me to answer my questions, listen to my concerns, and relate to me as a whole person. This is the healing aspect of medical care. Surprisingly the requirements, attitudes, and skills required, both from the patient and the physician, for curing as opposed to healing, are not just different. They are radically opposed [12, 13]. This central tension in medical care needs to be acknowledged and used for the benefit of the patient—the primary challenge and benefit of successful whole person care.

Since this separation of curing and healing was so clearly recognized by the ancient Gods, we have used a Greek symbol, the caduceus, to represent curing and healing. In Fig. 4.2 the white snake represents curing and the black snake represents healing. We have also used Greek historical and/or



Fig. 4.2 The caduceus symbol of whole person care

Table 4.1 The metaphor of the two snakes and the therapeutic dichotomy

	White snake Hippocratic	Black snake Asklepian
Patient		
Problem	Symptoms or dysfunction	Suffering
Possibility	Being cured	Healing
Action	Holding on	Letting go
Goal	Survival	Growth
Self-image	At the effect of disease	Responsible for coping with illness
Doctor		
Focus	Disease	Person with illness
Communication	Content	Relationship
	Digital	Analog
	Conscious	Unconscious
Power	Power differential	Power sharing
Presence	Competent technician	Wounded healer
Epistemology	Scientific	Artistic
Management	Standardized	Individualized
Process	Simple or complicated	Complex

mythological figures to represent the two sides: Hippocrates representing curing and Asclepius, the Greek God of healing, representing healing [14]. Table 4.1 outlines the very different requirements for curing and healing from the patient’s perspective and the physician’s perspective.

On the white snake or Hippocratic side of the table, patients come with a problem that they want fixed or cured. What they are attempting to do is to hold, on to survive. This is not just physical survival, but survival of their life exactly as it is right now. Their self-image is usually of being at the effect of a problem or disease that they want removed.

On this side of the table, the physician’s focus is disease. His/her communication concerns specific content information that he conveys by digital means and consciously. Each word he says has a specific meaning that could be looked up in the dictionary. Power is on the physician’s side and the presence she embodies is that of a competent technician. The epistemology used is scientific and the management aims at standardization. Depending on the nature of the problem, the process is either simple or complicated [15, p. 15].

On the black snake or Asklepian side of the diagram, the process is quite different. On this side of the table, the primary problem to be addressed is suffering, and the possibility being sought is healing. The action required from patients is letting go and opening themselves up to change and growth. They now begin to see themselves as responsible for coping with their illness.

The doctor's job is equally different on this side of the table. Her primary focus is the patient as a person, and the main aim in communication is now relationship which is primarily conveyed by analogue means. Analogue communication is well described by Watzlawick et al. as "posture, gesture, facial expression, voice inflection, the sequence, rhythm, and cadence of the words themselves, and any other nonverbal manifestation of which the organism is capable, as well as the communicational clues unfailingly present in any context in which an interaction takes place" [16]. Most of this analogue communication is unconscious. Power is now shared with the patient and the presence embodied by the physician is that of the wounded healer [17]. Since this aspect of the interaction uses the unique characteristics of the physician and patient, it is an artistic and individualized process—each such interaction will be different. The process is inherently complex [15]. Whole person care differs from other formulations of the medical mandate in explicitly including the facilitation of healing in the care patients need and in acknowledging the divergent attributes and requirements of curing and healing.

Divergent But Synergistic

There is no question that the processes of curing and healing, both from the patient's perspective and the physician's perspective, are radically divergent. However, the two sides are also profoundly synergistic. This can be confirmed by examining virtually any line on table 4.1. For instance, under communication, it is crucial for the physician to both know and convey content clearly and to communicate caring and relationship. If, as a patient, I realize that you know exactly what you are talking about, I am going to be much more open to a relationship with you. On the other hand, the better my relationship is with you, the more I am likely to listen to and trust the information that you are communicating and so on up and down table 4.1. These are two essential, divergent, and synergistic aspects of medical care, both of which need to be done well to provide optimum care.

A God Takes a Walk

But what does the staff between the two snakes represent? Robertson Davies tells the following story [18]. One day the Greek God Hermes was taking a walk when he noticed two snakes fighting. The snakes were in danger of

destroying each other so he thrust his staff between them preventing them from consuming each other, but allowing both to live side by side in a kind of creative tension. One snake represents knowledge and the other snake represents wisdom. There is a very close analogy to our two snakes of curing (a simple or complicated process requiring knowledge) and healing (a complex process requiring wisdom). And the staff represents the physician or other healthcare worker who holds these two divergent processes separate and synergizing like the two-sided man (or woman) referred to in Kipling's poem at the start of the chapter. We will examine the physician/patient relationship necessary for this balancing act in the chapter that follows.

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Chapter 5

Relationship in Clinical Practice

“If I am not for myself, who will be for me? But if I am only for myself, who I am? And if not now when?”

Hillel, Ethics of the Fathers, 1:14

It might seem that the dichotomous and complex nature of the doctor patient interaction means no simple model could be found to encompass this relationship. However, we have found that the model shown in Fig. 5.1 covers everything necessary for whole person care. It says that in any interaction with another human being, there is the self, the other person, and the context. The objective is to be congruent: to remain aware of all three elements—myself as a person, the other person as a person, and the context in which the interaction is taking place [1]. It is what the Hillel quote above suggests. One might wonder why we would ever do anything else.

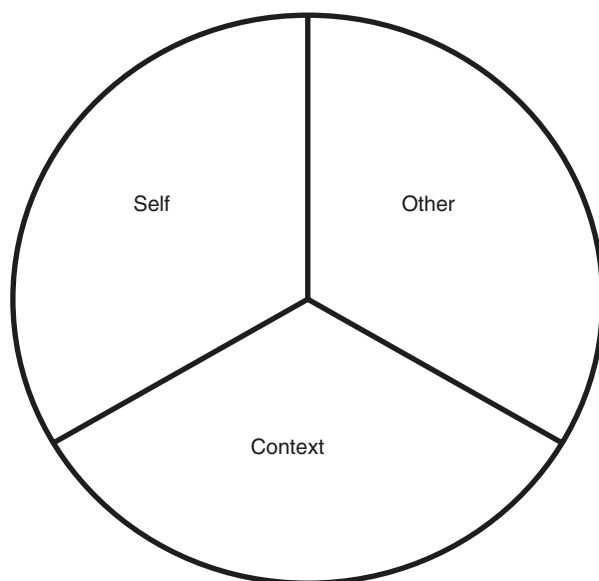


Fig. 5.1 Congruence

Communication Stances

Unfortunately, particularly when stressed, we unthinkingly omit one or more of these elements. The resulting communication stances are shown in Fig. 5.2. There are four primary communication stances [2]. In the blaming stance, we lose touch with the other person as a person, and our main aim is to have our expectations met. In the placating stance, we lose touch with ourselves as a person in the interaction. Our aim becomes solely to meet the other person's needs. In the super-reasonable stance, we lose touch with both ourselves and the other person as people. We become purely cognitive problem solvers. And in the irrelevant stance, we lose touch with all aspects of the interaction. This can be done by multitasking, by inappropriate humor, and sometimes with the help of drugs and alcohol.

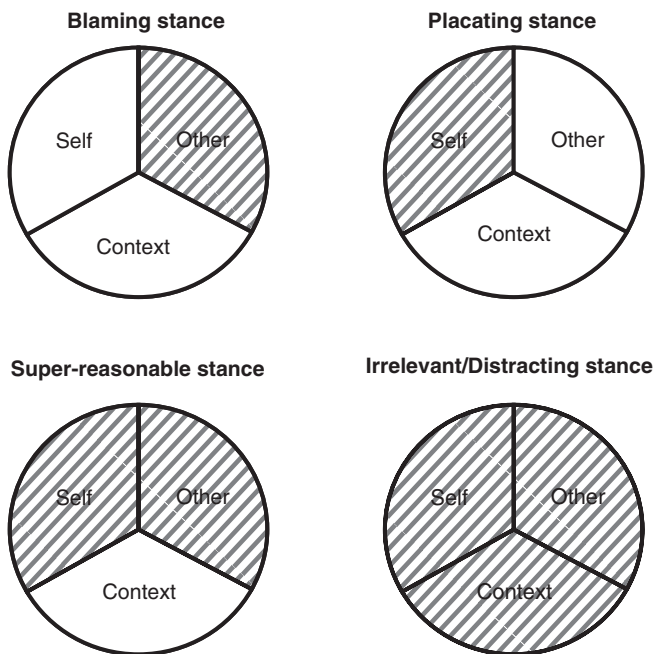


Fig. 5.2 Satir's communication stances

The Blaming Stance

In the blaming stance, we focus on ourselves as the person who must be accommodated. The patient must meet our expectations. This is the stance that underlies physician-centered care. We attempt as far as possible to avoid overt anger in clinical situations, but we have developed effective ways of adopting this stance. Terms such as dysfunctional, noncompliant, and personality disorder may at times be justified, but they can also be used to blame the patient.

The Placating Stance

In the placating stance, it is the patient who counts as a person. The physician or other healthcare worker is there solely to comply with the patient's wishes and needs. This is the stance that fits best with patient-centered care. It sounds like an altruistic and laudable approach. However, it is difficult to stay in the placating stance long-term without serious consequences to the well-being of the practitioner. Surprisingly, we have found that it is also not satisfying for the patients who are being placated. Perhaps initially it seems good but with time patients want to know the physician as a person and want her full collaboration as a person in the relationship.

Medicine and the Super-reasonable Stance

Perhaps because of the difficulties with the blaming and placating stances, physicians often gravitate to the super-reasonable stance in which they and their patients are both left out of consideration as persons. This is the stance that constricts medicine to a disease-centered focus. It is probably an attempt to relieve the emotional tension of blaming or placating, but at a high cost.

A colleague of mine, Dr. Balfour Mount, was hospitalized for esophageal cancer. The cancer was removed, and he was recovering in the intensive care unit. In the film "The Choice Is Yours," he describes the surgical team's visit [3]. They stood 2 to 3 feet from the end of the bed and recited

various blood results, including blood gases. One resident said, “He is bleeding rather heavily through his nasogastric tube.” The chief resident responded, “He is fine discharge him up to the room.” As they turned to leave, one resident turned to the other and said within Dr. Mount’s hearing, “It is such a shame, I suppose he should have six or seven good months left though.”

As Dr. Mount describes it, there was no eye contact and no acknowledgement of him as a person. There was also no acknowledgement of themselves as persons or their own feelings, which presumably were denied. Is this a rare phenomenon? We would say it is the standard operating procedure in medical practice. The aim appears to be to avoid messy and touchy-feely human emotions in the interests of clear thinking and dispassionate decision-making. Does it work in relating to patients? Dr. Mount’s rage at this treatment by colleagues is emblematic of the almost universal response of patients to this treatment as a case, not a person.

The Irrelevant Stance

It might be thought that the irrelevant stance would be rare in clinical practice as it involves losing contact with all aspects of the situation. Here is a report from one of our students [4]. “Probably my most disturbing day thus far. Surgeon J our surgical tutor brought us into an examining room. One of his pts [patients], Mr. K, walks in, an elderly man, and is surprised to see us—through his body language, I think he expects us to leave. Surgeon J tells Mr. K, briskly, to ‘drop’ his pants. Mr. K, looking at us, embarrassed, lies down on the table, fully clothed. Surgeon J walks over and while telling us about the pt’s illness, begins taking off the patient’s pants. Surgeon J asks med student D to do a testicular exam. Med student D asks Mr. K for consent; before Mr. K could respond, surgeon J begins to rant about how the patients ‘owe it to us’ to allow us to learn, and we should not have to ask for their permission. Med student D does his exam, Mr. K holds his hand to his forehead, obviously embarrassed. Leaving, Mr. K calls after surgeon J about some lab tests—surgeon J replies he hasn’t seen them and walks away quickly. Mr. K had an exasperated, frustrated look on his face. I’m sure he had many more questions”.

Clearly this surgeon was not behaving in a way that we would expect of a person in a caring profession. One would hope that this behavior would be rare, and yet we believe it has become increasingly common. We see it as a symptom of incipient and overt burnout.

Congruence

The ideal interaction is one in which the physician remains aware of him/herself as a person, the patient as a person, and the context in which the interaction takes place. We have found that both medical students and physicians can learn to do this fairly easily in training situations and undoubtedly some physicians do this most of the time in their practice. For most people, it takes a significant effort. Often the first step is to catch oneself in a communications stance and then make a conscious decision to put back in the missing part. It is often a three-step process: (1) I notice I have unconsciously adopted a stance, (2) I accept my reactive stance without judgment, (3) I make a decision whether I stay in the stance or move towards congruence. This is a moment-to-moment process that is a central part of effective clinical care analogous to an expert dancer or musician who is continually self-monitoring and making appropriate adjustments.

Clinical Congruence

The ideal approach to whole person care is clinical congruence. Congruent: present to self, other, and context. Clinical refers to the fact that this is a very specific situation in which the patient and the doctor meet as persons in a context in which there is a medical problem to be solved. The overlay of the clinical situation on the congruence diagram is shown in Fig. 5.3. It is clear from the diagram that clinical congruence involves both a focus on the disease and the doctor's role in curing or controlling it and the doctor's role in promoting healing. It is also important that there are lines (boundaries) separating the physician from the patient (I care about this patient, but he/she is not me) and from the disease (this is disease but not my disease right now). This clear separation is an important part of clinical congruence that is essential for effective action and long-term functioning.

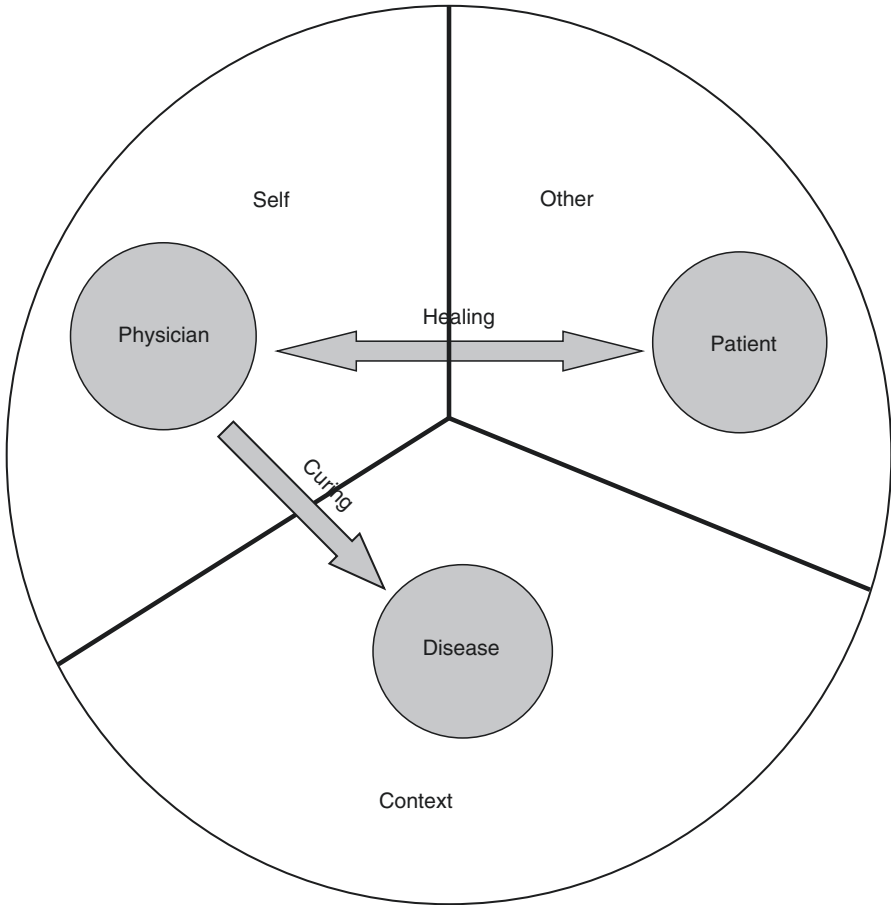


Fig. 5.3 Clinical congruence

A Painful Case

Mrs. Black was a single mother in her 50s with terminal colon cancer. She had worked as a union representative. The palliative care team was seeing her on a daily basis and it was not easy. The nurse and I would sit down at her bedside. She lay in bed, alert and looking unwell and not comfortable. We asked her about her symptoms. She had persistent abdominal pain, nausea, and frequent vomiting. I and some of my other colleagues tried everything that we could think of. Nothing worked. Every visit involved a change or adjustment in medication with no appreciable improvement in symptoms. On each visit, she would be quite clear that she expected us to

do better and asked what did we suggest. It was hard after a while not to feel like a failure. This was distressing to everyone, obviously including the patient. The staff on the floor were having a hard time coping, and the palliative care nurse asked to be excused from some of our visits. It was simply too painful.

After some weeks of this process, and helped by the fact that none of my colleagues whom I knew to be expert in the choice and adjustment of palliative medications could find a solution, I realized that we needed to pause and reflect on what we were doing. I decided that we had to stop changing medication. I also realized that we needed to do this in a way that did not blame her. It seemed to me that together we were involved in a dance—she blaming and we placating—that was not helping the patient.

The next time I went to visit her, I consciously adopted this new approach. I sat just as long, listened just as attentively, and attempted to be fully present, and when she asked what were we going to change, I said respectfully that we were not changing anything else for now. She accepted this, and to my surprise, in the days and weeks that followed, her symptoms improved somewhat. This was not any miraculous transformation but a slight and noticeable improvement in her symptoms and in our relationship with her. It was easier for us to be empathetic when we were not always struggling with a change in medication. She appeared somewhat calmer and also more present and less angry during our visits. We were more effectively accompanying a woman who was very sick and clearly dying with an untreatable cancer.

What do I think happened in this relationship? I believe that we changed from a placating stance, in which we always felt we were not good enough or doing enough, to a stance closer to congruence. We accepted that we were doing what could be done and were powerless to do more. We were not deficient, just defeated by symptoms we could not control. I believe the patient changed from a primarily blaming stance, closer to congruence. She accepted that we could not do more and demanding more would not help. She seemed to respect and value us more. It was a real, if limited, win-win situation in which both parties moved towards congruence.

An Ongoing Challenge

Although in principle congruence is an easy concept to understand, in practice it is extremely challenging. It is a balancing act in which our internal reactions and the responses of the patient continually tend to push us off

balance. We are balancing on a high-wire rather than walking on a flat surface. And to stay congruent, we require a complementary way of being that is discussed in the next chapter.

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Chapter 6

Mindfulness in Medicine: Space, Slow, and Flow

“The funny thing about time in the OR, whether you race frenetically or proceed steadily, is that you have no sense of it passing. If boredom is, as Heidegger argued, the awareness of time passing, then surgery felt like the opposite: the intense focus made the arms of the clock seem arbitrarily placed. Two hours could feel like a minute.”

Paul Kalanithi. *When Breath Becomes Air*

Space

In introducing mindfulness to medical students [1] and physicians in practice [2], we do an exercise on making space for themselves in their lives. The group is divided into pairs. One person asks the other, “What do you notice when you *don’t* make space for yourself in your life?” This question is repeated as soon as the responder stops speaking. We then continue the exercise with the opposite question, “What do you notice when you *do* make space for yourself in your life?” The difference that people notice in the response to these two questions is striking. In particular they notice that in response to the second question, they identify all sorts of good results such as more creativity, productivity, and improved relationships. These are often the results that they had hoped to achieve by staying busy, trying harder, and making less space for themselves in their lives. They realize that the world is actually turned on its head and counterintuitive. By making more space for ourselves, we actually enhance our ability to contribute to the world.

Slow

This is the first step in mindfulness [3], the intention to make more space for ourselves in our lives. This is an intention that is not specific to mindfulness but is shared by other movements to improve the quality of our lives. This is the intention of the slow movement [4], whether it is slow food or slow

work. The realization is that in the busyness of our lives, we rush everything and miss the enjoyment and value of our experiences [5]. We need to slow down. It is easy to understand this in recreational activities and nonwork activities such as eating food slowly, but can it work in a medical work environment?

I believe that it does work, that patients want it, and doctors and other healthcare workers need it. I believe that it is at the heart of the complementary and alternative medicine (CAM) movement [6, 7]. It is not that the specific interventions and treatments of CAM are better, but that CAM deliberately adopts a slow approach to medical practice. CAM practitioners spend more time with their patients, listen more attentively, and often prescribe treatments that take more of the patients' time. The whole effect is a slowing down and a respect for the body's natural ability to heal.

Could this same attitude of slowing down become a normal part of conventional medicine to the benefit of patients and healthcare workers? I believe that it could and it must, and this is exactly the intention of the whole person care movement. The idea of whole person care is not to adopt the specific treatments of CAM but to combine the attitude and intention of CAM practitioners with conventional medicine. There is no reason that a medicine that understands so much about the scientific underpinnings of how the body works down to a cellular level and how to use that information to treat disease should not also embrace an understanding and a relationship to the whole person.

I recall a patient on hemodialysis treatment for chronic renal failure due to polycystic kidneys. Let us call her Mrs. H. She was from Turkey and did not speak English very well but she and I had known each other for a long time, including an episode when she had a cardiac arrest while I was speaking to her outside the dialysis unit. The arrest was due to a very high potassium level (a complication of kidney failure), and she was successfully resuscitated to continue on her dialysis treatment. We will return to my response to that episode (not slow), but for now I want to speak about her regular checkups. In the dialysis unit where I worked, every patient had a primary care doctor who met the patient for a full evaluation and review outside the dialysis unit at least once per year. Mrs. H was my patient and I remember her reaction to one particular review. It took a little over 1 h during which I examined her, reviewed all of her results, went over her medications, discussed any changes I thought that we needed to make, and attempted to answer any questions that she had. The review itself went smoothly and I had done many similar ones with Mrs. H and my 25 or so other primary patients. It was satisfying for me to feel clear we were on top of things. For Mrs. H the result was apparently more dramatic. Later that day I met a nurse who asked me, "What did you do to Mrs. H? She acts like she has wings on her heels since your evaluation." Surprising? Well, perhaps not, because I believe that is exactly how I would have felt if someone with detailed knowledge about medicine and my

situation had taken the time to review it all with me. It might feel like a fresh start, a sense of relief that whatever the situation, we had it under control.

Was I slow with Mrs. H? Well yes, in the sense that I took time and was not rushed, but not artificially slow. What we are searching for is the *tempo giusto* [4, p. 38] which brings me back to Mrs. H's cardiac arrest. Did I react slowly to Mrs. H's arrest? Of course not! In fact, I had her on the floor, pumping her chest, calling for the arrest team, and otherwise organizing her resuscitation very rapidly indeed. There was not a second to lose if we were to succeed not just in bringing her heart back but in ensuring that she did not develop brain damage. It worked. Sometimes we need to slow down and sometimes we need to speed up, and what we are searching for in addition to the intention to make space for ourselves and others is the attention to the moment that allows us to respond in the best way possible.

Attention

The key to good medical practice is the control of our attention. Is this easy to do? Absolutely not. Most of us spend our lives with an attention that is repeatedly distracted from our main task or intention. I get on to the computer to search for a specific e-mail that I need to respond to. In the process of scrolling down I notice a new e-mail from an acquaintance I haven't heard from in a long time. I open it up and after that another e-mail looks interesting, and completely unintentionally I have become distracted from my original intention. Does this happen in medical practice? I believe it does.

Mindfulness

Training in mindful meditation does two things. First, when we try to meditate on our breath or a part of our body, we realize how difficult it is to direct our attention consistently and how easy it is to become distracted. Most people cannot keep their attention on their breath for more than a few seconds without some distraction, and it is not infrequent after a 10-min sitting meditation to realize we have been thinking about some unrelated event for most of the time. Simply realizing how easily we can be distracted is an important lesson because we realize that attention is not something we can take for granted but needs to be constantly monitored and directed.

The second benefit of mindfulness training is learning monitoring and adjustment. We are exercising a muscle. When we notice our attention has become distracted from the breath, we gently return it to our intended focus. These two processes of noticing and then returning to the breath are the same

skills we need in a conversation with a patient. The patient says something or we think of something that distracts us from the conversation and we miss a beat or two. That is OK as long as we notice it and return our focus to the patient in a way that allows the conversation to flow and develop. Training in mindfulness can help us to do a better job in managing what will always be a potentially wandering and imperfect faculty of attention.

Flow

However, training in mindfulness is not the only factor in ensuring our attention. Most of us have had experiences where our attention was completely riveted to the task at hand without any conscious effort on our part. This usually occurs in a structured activity where the stakes are high enough to make all other considerations, for the moment at least, seem trivial and not worthy of our attention. This can include even our own comfort. Some of us have had the experience of a headache disappearing in the midst of making a presentation at an important meeting only to have it return when the meeting is over. What we are experiencing is a phenomenon called flow that is highly relevant to medical practice.

Some of the characteristics of flow as described by Csikszentmihalyi [8] are that it occurs in the course of well-defined activities at which we have sufficient expertise to feel confident in our abilities and that provide us constant feedback on how we are doing. Good examples are athletic competition and some forms of intense work, during which we may lose a sense of ourselves [8, p. 64] and even of time [9, p. 104]. For most people, this is a very satisfying experience and Csikszentmihalyi would say that it is an important source of happiness and a high quality of life [10]. For some people, flow is so enjoyable that they report that work stops being work [11].

Some aspects of medical practice naturally encourage flow. Surgery is perhaps the quintessential example, and I believe it is an experience of flow that Kalanithi is describing in the quote at the beginning of this chapter. Surgery includes preparation beforehand involving gloving and gowning, a focus on a particular task in an environment that is deliberately set up to prevent outside distraction, continuous feedback from what is happening at the operation site and on the patient's physiology (from the anesthetist), and a clear-cut end point when the operation is complete and the skin is sewn up. Are there other parts of medical practice that foster flow?

In my own experience as a nephrologist and later palliative care physician, I can think of a number of such activities. The first are procedures in general, including placing a catheter for dialysis treatment and activities such as a spinal tap. These are very analogous to surgery including the prior preparation and sterilization, continuous feedback, freedom from outside distractions,

and a clear-cut end point. What about the nontechnical aspects of care? I have experienced exactly the same phenomenon in family meetings aimed at resolving a difficult issue in care. There is the same prior preparation with the team, continuous feedback, freedom from outside distraction, and a clear-cut ending. I have also experienced a similar phenomenon in interviewing a dying patient and occasionally in an important clinic visit with an outpatient. My question is should we not be attempting to turn more of our clinical work into opportunities for flow? Looking at pictures of William Osler examining a patient at Johns Hopkins Hospital 100 years ago [12], where he goes through ordered steps of observation, palpation, auscultation, and contemplation, I see a clear process that would favor flow. Is this possible in our busy modern practices where there seem to be so many electronic and other distractions?

I believe that it is possible if we are clear about our intention and willing to make the commitment to a form of practice that creates space for full attention to the particular clinical task at hand (whether it is operating on a gallbladder or listening to a patient). I believe that training in mindfulness is a useful way to prepare for such a practice. However, we also need to structure our practice in a particular way. Rather than be carried along by the busyness and distraction of our environment where one task runs into another, we need to divide our work into clear-cut doable and separable jobs, each with a clear-cut beginning, middle, and ending and a continuous source of feedback. This could be done in different ways at a clinic, in ward rounds, and so on, but we need to create a space that allows us to bring to all aspects of our work the same undivided attention that we currently reserve for special situations such as surgery or procedures. For flow to occur, we also need something else.

Deeper Purpose

I believe for us to bring the full attention that we need to see in medical practice, we need to repeatedly remind ourselves that for us this may be a routine interaction but it almost certainly is not routine for our patient. This is why whole person care requires that we continually make the effort to empathize with our patients. Empathy brings us in contact with the important and high-stakes nature of medical practice for our patients.

But what about for us? Doesn't our practice also need to be important for us as a person? Yes, we may empathize with our patients, but will that be enough over the long term to keep us fully engaged in our practice? Different people would express it in different ways, but Viktor Frankl would say that we need to find deep personal meaning in our work [13]. Not just the meaning that this job pays the bills or will lead to promotion or recognition. For long-term experience of flow, we probably need to feel that we serve a cause or purpose larger

than ourselves [13, 14]. For some it may relate more to the relief of human suffering and for others the eradication of disease, but I don't believe that any long-term practice of whole person care with mindful attention and flow is possible without some profound source of meaning that resonates powerfully for us. And to begin to heal the soul of medicine we need to bring this meaning and attention to every interaction we have with a patient under our care.

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Chapter 7

The Process of Whole Person Care

Process: “A series of actions or steps taken in order to achieve a particular end.”

Oxford Dictionaries

And the particular end in this case is the relief of suffering. In each interaction with a patient under our care, we need to bring our full selves to the clinical context (mindful clinical congruence) and to follow a very straightforward series of steps. There is a natural order to this process, although there is also movement back and forth between individual steps.

Step 1. Clarify the Diagnosis

Whether it is a first visit or a return visit for a patient with a chronic condition, patients want to know what is going on. Making a diagnosis is something that physicians are empowered to do [1], and it is the first important step in relieving suffering. Suppose you have had a viral infection and are still coughing 6 weeks later. You go to see your physician to find out what it means. Are you suffering? Almost certainly yes. Not perhaps because the cough is so bad or significantly interferes with your life but because of what you fear it may mean. Most of us with an unexplained symptom will have thought up many possible explanations that are very threatening. Explanations such as a possibly serious infection, the onset of a threatening disease such as lung cancer, and some other chronic condition will almost certainly have jumped to mind. Of course, we will have tried to dismiss them, but if we had been completely successful we would probably not be visiting the doctor. The key insight related to this first step is that virtually all patients who come to see a doctor are suffering because they are worried about some potential threat to themselves.

Healthcare's first job is therefore not bland reassurance or dismissal of symptoms and their attendant worries but making a diagnosis that separates the patient from the disease or problem [2]. This in itself goes a long way to relieving suffering. In the example of the post-viral cough mentioned above, it may be enough for the physician to listen to the symptoms, examine the chest, perhaps look at a chest X-ray, and clarify for the patient that this is a common problem after viral illnesses and does not represent a serious threat. This separation has a direct effect on relieving suffering. It says you as a person remain intact. As Aronowitz points out in *Making Sense of Illness*, this is a key element in medical care [3]. It is the first step in relieving suffering.

Step 2. Clarify the Prognosis: The Patient's Perspective

We normally think of prognosis in terms of Kaplan-Meier survival curves or other medical statistics concerning the length of survival or likelihood of cure. This is not what is meant here. We are dealing with a suffering human being who perceives a threat to himself as a person. We need to explore what those perceived threats are and our best judgment of what the future may bring in these terms. This takes considerable listening and sensitivity to what the patient is asking and what she/he is ready to hear. Buckman's process of breaking bad news [4] works very well here, and even if the news is not bad, the SPIKES model works very well. In my experience, clarifying the situation for the patient in response to what the patient already knows and wants to know almost always goes a long way to relieve suffering. As we mentioned at the start of this book, this can be true even when the news is very bad indeed—remember the patient in Chap. 1 who found that the pains and aches in his pelvis and thighs when running were due to metastatic cancer. Sometimes we increase suffering by the way we handle this aspect of the medical interaction. I recall a patient who after developing renal failure understood that he would be attached to a machine for the rest of his life [5]. What was meant was that he would need regular dialysis treatment (three times per week for 4 h), but he imagined himself literally attached to a machine—extreme suffering.

Step 3. Treat the Disease

This is the part of medicine with which we are most familiar and in which the greatest development have been made. There is no question that effective treatment of disease can go a long way to relieve suffering. At its most

simple, this can mean giving an antibiotic to cure an infection. However even here, it is not an open and shut case. This infection may be cured, but the patient may worry (perhaps very reasonably) whether the infection will recur, what the development of this infection means for their overall health, and do they have weak lungs, weak kidneys, a deficient immune system, and so on. So even with effective treatment, responding to the patient's concerns remains highly relevant.

And treatment itself also causes suffering. It may be as simple as the threat to my sense of myself represented by the need to take this pill. I suspect that this is a potent cause of noncompliance. But with more invasive treatments, this becomes a very severe cause of suffering indeed. Examples include major surgery, chronic dialysis treatment for renal failure, chemotherapeutic regimes for cancer, and even regular insulin treatment for diabetes. At least in the initial phases and possibly indefinitely, these kinds of invasive treatments can represent a severe threat to a patient's sense of her own integrity as a person. This does not mean that these treatments are not worth doing. However, if we are clear that our mission is the relief of suffering, we need to take significant time and effort to negotiate and clarify such decisions with patients. Some people may decide not to undergo the surgery nor start the dialysis as the suffering involved with treatment would be greater for them than dealing with the disease untreated. And whatever course patients decide on there is a fourth step that is always relevant in the relief of suffering.

Step 4. Create a Healing Relationship

Whatever disease patients suffer from and whatever treatment they receive, they will always need support for their own intactness and importance as a whole person. This will come from many sources, including family and friends, but healthcare workers and physicians play a key role [6]. We know more about the disease, its prognosis, and treatment, than the patients or their families. We are often privy to more of the patients' fears and concerns, and have a unique power to either honor the patients as people (helping to relieve suffering) or dismiss and dishonor them (greatly increasing suffering) as they go through the process of healing in response to disease. It is worth remembering that all disease (even imagined disease) causes a threat to our sense of ourselves and that the healing response to this is a form of change and growth for which patients need support. Given our origins as a profession in history and prehistory which did not involve much cure of disease, our main role has always been to provide such support.

This has not become any less important as our therapeutic armamentarium has increased, and given the potential increase in suffering with invasive life-prolonging treatments it is probably more important than ever. If, as I believe, our overriding purpose is the relief of suffering, then the ability to relate to a patient as one whole person to another in a way that supports the healing journey is the bedrock on which the rest of healthcare practice depends. How we perform this crucial task and the other steps in the care of the patient, sometimes sequentially and sometimes simultaneously is the art of medicine that we will discuss in the next chapter.

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Chapter 8

The Art of Medicine

“Art is not the possession of the few who are recognized writers, painters, musicians; it is the authentic expression of any and all individuality.”

John Dewey

In *A Portrait of the Artist as a Young Man* [1, pp. 205–8], Stephen Dedalus explains to his friend Lynch the difference between proper and improper art. Improper art according to Stephen is kinetic. It drives us towards something or away from something. Proper art produces stasis. It arrests the mind in the appreciation of aesthetic beauty so that we are not simply reacting out of attraction or aversion to the object of our attention but are raised above desire and loathing.

Aesthetic Appreciation

In that arrest, according to Stephen, there are three essential stages: wholeness, harmony, and radiance [1, p. 212]. These elements based on the ideas of Aquinas and Aristotle have the following attributes: wholeness comes from the separation of the object from the rest of the world, which now becomes background; harmony arises from noticing the relationship between the different parts of the object; and radiance is to quote James Joyce, “The instant wherein the supreme quality of beauty, the clear radiance of the aesthetic image, is apprehended luminously by the mind.” This last stage is the least under our control and difficult to define precisely, but anyone who has attended a great play or read a great book has had the experience. It is that indefinable something that you are left with when you leave the theatre or put the book down for the final time.

Empathy

Is this phenomenon part of medical practice or should it be? What would it look like? At one point in my career when I was contemplating a move to palliative care, I spent a month on a palliative care ward as a volunteer. I remember particularly one man who was dying with a metastatic cancer but was ambulatory and able to do most things. I was walking along a corridor with him and one or two other patients. The conversation concerned what they wanted for themselves. This man said, “What I really want is to get better and get out of this place.” Then, looking around somewhat furtively, he added, “but you are not supposed to say that around here.” For me it was an experience of luminous clarity.

In that moment I could empathize with him in a much deeper way than previously. It felt like a direct experience of standing in his shoes for an instant. A video created by the Cleveland Clinic [2] produces this kind of effect repeatedly as we watch a series of patients, family members, and healthcare workers and hear what is going on beneath the surface of their ordinary activities. It is a series of aesthetic arrests that sends us away with a deep senses of what it means to work in healthcare, a presence to mystery rather than problem solving; in Joyce’s words stasis rather than kinesis.

Mindful Practice

How do we bring this way of being into our practice? There are probably many ways, and perhaps formal aesthetic appreciation should be part of medical education. There may also be a simpler way. Joyce’s three stages of aesthetic appreciation (wholeness, harmony, and radiance) can easily be translated into a mindful approach [3] to medical practice in the following direct way:

1. Wholeness = Intention: to focus on this person before me as a whole and separate human being
2. Harmony = Attention: to pay attention to the different aspects of this person and our interaction including the connections that make her a unique person
3. Radiance = Awareness: to be open to an appreciation of this patient as a whole person

What does the aesthetic perspective add to a mindful approach to medicine? An older colleague at another institution once commented on

mindfulness, “Just keep eating your porridge.” I know what he meant. As it is sometimes taught, it is difficult to see where is the excitement, the joy, the transcendence in simply returning again and again to the breath. But that is just the training aspect of mindfulness meditation. Just like repetitively lifting a weight at the gym, it is not very exciting or enlivening but can strengthen a muscle for what really interests us—the skiing or the football game. What we need is to apply the focus of attention and awareness that we have learned combined with real curiosity and excitement to our work and our patients; it is the same kind of attention that we would apply to a great work of art. What does the proper art of medicine require? Appreciating the wholeness, harmony, and radiance of our patients.

The Bounded Clinical Interview

How do we enact this appreciation in clinical practices? The key, I believe, is the medical interview and the boundaries we place around that interaction. Normally when we think of boundaries, we mean something we place around ourselves, often as a measure of self-protection. But the boundaries I am speaking of are more akin to the frame around a painting, which Joyce would suggest is the first step in fully appreciating an object or work of art. But it is not a painting that we are contemplating, not a still life if you will, but a living interaction. If we are artists, we are performance artists.

If works of visual art occur in space and works of aural art occur in time [1, p. 212], our art combines both and includes action. It is more like a ballet than a painting. And like a ballet, to be fully performed and appreciated, it needs boundaries to separate it from what came before, what follows it, and what competes for attention while it is being performed. The performance also needs to combine seamlessly both the curing and the healing sides of the medical dichotomy.

How does this look in practice? When I would enter the room of Mr. K, the patient with lung cancer described in Chap. 1, I would remind myself first of the incalculable importance of this interaction to him on this day at this time. I attempted to empty my mind of expectations and open myself to the situation as it was right now. I would then greet him, and begin the interview. The first frame or boundary of a clear beginning had been set.

The interview would often start with practical and fixable issues, such as pain control and adjustment of medications. It would then weave back and forth between these “curative” kinds of concerns and other issues including where he wanted to go next (home? palliative care?) and stories about himself that he very much wanted me to know. I would engage my full attention

in the interaction and would be both listening and speaking, all the time attempting to stay open to what was emerging, while giving shape to the interview. I would be striving to move towards a satisfactory completion of what could be achieved and appreciated on that day. At some reasonable time (this was not an open-ended process), I would be moving to end the interview in a way that left both of us with a sense of a step taken, and the freedom to separate as one would leave a play or ballet. What had transpired might stay in the mind as an after image, but this particular performance was now over, and it was time for me to turn my attention to the next patient to be seen or task to be completed. Interestingly, it was often just after I had left the room that the full impact of the interview would hit home. When it had gone well, I would have a sense of being deeply touched, often felt as a sensation in the epigastrium—Joyce's radiance.

Day-to-Day Practice

Is it possible to practice like this on a regular basis? I would say that it is not only possible, it is essential. And the system in which we work may facilitate this way of working or make it very difficult indeed. I have experienced these effects in different contexts. In covering an inpatient unit and a consult service in palliative care, I found that it was possible to behave in this focused way, one patient at a time, most of the time. There were frequent pressures from the people that I worked with who often wanted an answer to their question or concern now or were worried about their own schedule. There were virtually no obstructions posed by patients. Once I was clear on my focus, which was to make each interview with each patient as helpful, deep, and complete as possible, the rest of our work flowed easily. I was aware that this did not actually take more time, merely more mental discipline and focus than if I simply went with the drift of business as usual. Ultimately this is a more energizing and satisfying way of practicing that I and the people working with me found enjoyable and productive.

I have been in other situations where this approach was feasible. Interestingly, it did not necessarily have to do with being less stressed or busy. As an intern, where I was still learning my trade, I adopted this approach fairly instinctively because I realized that I needed my full focus with each patient to get the job done competently. Practicing nephrology in a clinic setting, the patient by patient focus was relatively easy and led to many long-term satisfying relationships with the people who became my patients. But at times the system seemed to conspire to make the mindful approach difficult or impossible, at least for me.

The clearest example of a difficult clinical context for me was covering a dialysis unit. In the particular unit in which I practiced, each nephrologist would cover the unit for a month at a time during week days. This meant seeing roughly 75 patients per day, 25 in the morning, 25 in the afternoon, and 25 in the evening, in addition to being available between visits for anything that came up during the day. I never failed to be defeated by this task. I would usually leave the unit with a sense of incompleteness and sometimes fear (what had I missed or failed to address adequately?). At the end of the month, my brain would be frazzled. I remember after one of these months walking like a zombie away from the hospital for a coffee and a day of wandering around town to give myself time and space to recover from the month of overload.

What was the difficulty here? The biggest problem was making a clear and satisfactory transition between one patient and the next. This was made difficult by the proximity of the patients at their dialysis stations within the unit so that there was not a natural break between them, no obvious trigger to let the previous patient go and to focus on the new patient before me. There was also the natural incompleteness of each interview. Patients with chronic renal failure have so many medical problems that it was very difficult to be sure that a nonspecific complaint such as fatigue or a diffuse pain did not presage something more serious which was difficult to explore sufficiently with each patient to get to the bottom of the matter. The result was an accumulating weight of uncertainty and doubt that was carried from patient to patient and tended to exhaust and overwhelm the mind and spirit, a state in which it was exceedingly difficult to be mindful, congruent, and focused. Neither the curing nor the healing side of medicine was done well.

Next Steps

What can we do to make space for the art of medicine in all areas of practice? First, we need to embrace the idea that the practice of medicine is an art, as much of an art as music, dancing, or painting. Like all of those arts, it has a technical side that needs to be mastered, but the artistry consists in combining that technical skill with something deeper. In music this would be called musicality. In medicine it is the ongoing integration of treating disease and the creation of a healing relationship with the patient. Second, like any work of art, it needs to be separated from the rest of the world, to be focused on and considered something complete and whole in itself, like listening to a symphony concert rather than the same notes as background music. This applies to our overall relationship with each patient and to each

of our interactions with a patient. We need to begin to think seriously both as individuals and as a group about the requirements to make possible the proper practice of this ancient art so that, as the Dewey quote at the beginning of the chapter implies, the practice of medicine can become an authentic expression of our individuality. In the next chapter, we will examine a phenomenon that can be either an ally or an enemy in this process.

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Chapter 9

Death and Death Anxiety

“When a man knows he is to be hanged in a fortnight, it concentrates his mind wonderfully.”

Samuel Johnson

In a recent meeting with physicians from the pediatric emergency room, I had them do an exercise that we also do with the second year medical students. Each person was asked to write down five goals and dreams for their life. They then shared their list with the person sitting beside them. I asked them what their list would be if they knew they had 1 year to live. Then they revised the list again supposing that they had 1 month to live and finally 1 day. What was surprising, although expected from our experience with medical students, is that as the imagined time left became shorter, their lists became more and more similar and their primary concern became expressing love and feeling love from members of their close family.

After the exercise was complete, we discussed the results in the large group of 12 physicians. People expressed in different ways that they felt, as imagined time was shorter, that they were getting more and more in touch with what was really important to them, and love became more important. In a strange way, facing death appeared to open them up in a way that was wholly positive. At first glance, this observation did not appear to fit with research on death anxiety and terror management theory.

Sheldon Solomon

I met Sheldon Solomon for the first time when I invited him to speak at a day on whole person care as part of a Palliative Care Congress in Montreal. Sheldon is a Ph.D. psychologist, university professor, and world expert on death anxiety. I remember that day he did not use any PowerPoint slides, spoke from the floor of the room at eye level with the audience of 200 physicians and other healthcare professionals, and was absolutely spellbinding.

As a friend of mine who is a senior oncologist and has heard many talks said, “It is rare when someone tells you something that is completely new, but Sheldon Solomon does exactly that.” Sheldon and his colleagues Tom Pyszczynski and Jeff Greenberg are the world experts on how we deal with our fear of death, a topic they have named terror management theory [1]. Their findings are relevant in a whole variety of contexts, including how the world deals with threats of terrorism, but for our purposes they are particularly important for the practice of whole person care [2].

Death Anxiety

According to Solomon et al., we all have death anxiety lurking in our subconscious most or all of the time [3, p. 55]. And when we trigger this death anxiety closer to consciousness, interesting things happen. Their first experiment was with 22 municipal court judges in Tucson, Arizona [4]. The judges were told that the researchers were studying the relationship between personality traits and bond decisions—how much money a defendant must pay before a trial to be released from jail. What the judges did not know is that what the researchers were really interested in was the effect of mortality salience (thinking about their own death) on their judgments. So some of the judges (the mortality salient group) were asked to respond to questions that made them think about their own death. They were asked, for instance, to “Please briefly describe the emotions that the thought of your own death arises in you” or “Jot down, as specifically as you can, what you think will happen to you as you physically die and you are physically dead.” The results on their judgments were striking.

When the judges were asked to set bond for a hypothetical case of a woman accused of prostitution, those in the mortality salient group gave very different responses to those in the control group. In the control group, the average bond set was \$50, whereas in the mortality salient group, the average bond was \$450, almost ten times higher. The researchers interpreted the findings as supporting the hypothesis that mortality salience causes a greater attachment to one’s own cultural worldview and a greater intolerance for people who transgress that view, as the prostitutes were assumed to do by these judges. These researchers have gone on to study this effect in a variety of settings, including medical settings, always with similar results [1]. Mortality salience makes us more attached to our own cultural worldview and more negative to people with a different view of the world.

Proximal and Distal Defenses

According to Solomon et al., we have two sets of defenses against the vulnerability induced by triggers of mortality salience [3, pp. 59–60]. They describe the immediate or proximal defenses in various ways, but the mechanisms appear to be distraction, denial, and suppression. This works for a time and serves to deal with the immediate threat posed by having our mortality salience triggered. It may be because of the effectiveness of these proximal defenses that many people deny that they have anxiety about their own death. However, these defenses cannot be kept up indefinitely, as they require significant cognitive processing, and the mind needs a more effective mechanism to defend itself.

The more effective mechanism is referred to as the distal defenses. In the distal defense mechanism, we ally more closely with those who share our worldview and distance ourselves from those who do not share our values. The theory is that the realization of our own mortality is a threat to our self-esteem and that we defend against this threat by associating with a group that bolsters our sense of our own value and by distancing ourselves from those who do not share our values. We now devalue these others and thereby bolster our own self-esteem by increasing the value we attribute to our group. These researchers see this as a universal process, even going so far as to give it as the explanation for the development of coherent cultures in the first place [5, pp. 18–22]. Regardless of whether we accept this hypothesis or not, they make a strong case that when threatened this is why cultures attempt to devalue and even destroy groups with competing worldviews, a phenomenon they see at work in many world conflicts [5, pp. 29–34].

Death Anxiety and Medical Practice

Since medical practice is bombarded with potential triggers to mortality salience, it would not be surprising that the phenomena described by Solomon et al. should be active in medical practitioners. They have done studies with medical students showing that when their mortality salience was triggered, they were more concerned about the threat of cardiac findings to patients who shared their religious beliefs than to patients who had different beliefs and would potentially treat them differently [6]. But the phenomenon may be much more ubiquitous in medical practice than the example above suggests.

Terror Management Within Groups

What happens when our death anxiety is triggered but there is no obvious cultural or religious group to treat as other? The same researchers have studied this phenomenon by examining the effect of mortality salience on how students view members of their own group who either agree with them or disagree with them over their preference between the paintings of Paul Klee and Wassily Kandinsky [7, p. 77]. When their death anxiety is not triggered, students can tolerate colleagues who disagree with them without negative judgment. However, when their death anxiety is triggered, students had more affection for those who shared their judgments and felt more negatively about those who disagreed with them. The implication is that even when there is no obvious reason for identifying people as other, we will find such people when our death anxiety is triggered [7, p. 77]. The researchers posit that this is a function served by identifiable minorities in any culture. They supply the need for an identifiable other to whom we can feel superior thus bolstering our self-esteem and helping to fend off our death anxiety.

The Special Case of Medical Practice

How would this apply in medicine? Patients are an obviously separate group to whom physicians and other healthcare workers can easily feel superior by virtue of their own professional expertise. And there is another phenomenon at play here. Not only are patients identifiably different by virtue of their status as patients, they are also clearly vulnerable people on whom it would be very easy to use another defense mechanism. As Samuel Shem says in *The House of God*, “The patient is the one with the disease” [8, p. 420]. We can imagine a very effective self-esteem bolstering and self-protective worldview that would go something like this. “In the scheme of things patients are sick and I am well; this means that if someone is going to die it is more likely to be them than me. So I can feel both superior in view of my professional expertise (self-esteem bolstering) and relatively invulnerable (self-protection) by comparison to these obviously sick human beings.” It should be stressed that this can all be done unconsciously without negative intentions and without overtly negative judgments of patients. As Solomon et al. have shown, people can actually appreciate minority groups within a population because they serve this effect of self-esteem bolstering and relief of death anxiety [7, pp. 78–81]. I realized that I had used this worldview of medicine for a long time in my own practice when one of the players stepped out of character.

A Sick Nurse

When I was a nephrology staff person early in my career, I met a nurse who clarified for me in a very striking way what my defenses were against illness and death anxiety. This was a person with whom I had worked closely when I had been on the kidney transplant program. She was a delightful person whom I had come to know well. We were not close friends, but my wife and I had socialized with her outside work on a number of occasions. A number of years later, not having seen her in the interval, one of my colleagues asked had I heard that Ann Smith (not her real name) had metastatic breast cancer.

I was aware of strong feelings of fear and rejection that I pushed away but the feelings resurfaced when I met her soon afterwards in the hospital. I could barely speak to her. The conversation was extremely short; I did not mention her illness and got away as soon as possible. Even at the time, I was shocked at myself and somewhat ashamed. How could I treat this person with so little compassion and respect?

My nursing friend had broken the rules. She showed all too clearly that there was no guaranteed safety on the medical side of the healthcare divide. My defenses collapsed. These included elements of distraction, denial, and suppression, but there was a fourth more potent defense. This defense has strong elements of Solomon et al.'s distal defense mechanism. However, it is not just a case of conflicting worldviews but a *projection* of my vulnerability onto another group, in this case patients. In this formulation, it is not just that people distinguished as other threaten my worldview and self-esteem; it is also that I need them to bolster my sense of security when they take on my vulnerability. And when one of my own group shares this vulnerability, the defense effectively collapses.

Reaction

One way of describing the defenses against death anxiety whether described as proximal or distal defense mechanisms is that they are reactions—automatic, unchosen, and largely unconscious [3]. This is exactly what the multiple excellent experiments done by Solomon et al. are designed to detect. It is the desire to uncover these reactions common to all human beings that makes the deception inherent in these experiments so important. Subjects have their death anxiety triggered but are not told that the experiment concerns confronting death anxiety [3, 7]. And indeed when subjects were encouraged to more openly confront their fears of death, the mortality salience effects decreased [3, p. 56].

Response

What happens when we *choose* to respond by deliberately facing our own mortality? My clearest experience of this was when I began to work in palliative care where directly facing death was part of the mandate of the team. A completely different process ensued. I found myself more open, more present, and, surprisingly, less anxious and more calm. I believe that this is why in Buddhist teaching, meditation on death is considered the royal road to mindfulness [9].

And it is not just Buddhists who have noticed this phenomenon. In his wonderful short story “The Dead,” James Joyce describes exactly the same process [10]. Gabriel Conroy has had his death anxiety triggered by thinking about his aunts who have just hosted a celebration at their house. He consciously thinks of the impending death of one of his aunts, who looks frail. Back at the hotel with his wife, he notices that she is acting in a somewhat distant way. It turns out that she has been thinking of a previous lover who has died, and as Gabriel takes in the full weight of what she is experiencing, his initial jealousy turns to caring and compassion for his wife and her dead lover and finally, it seems, to a broader awareness that encompasses wider and wider fields of consciousness, ending with imagining the snow that is falling outside his window blanketing all parts of Ireland, including the living and the dead. It is a moment of profound transcendence triggered by contemplating death.

Congruence and Death Anxiety

The proximal defenses against death anxiety use the mechanisms of distraction, denial, and suppression. The primary mechanism of the distal defenses is projection. These four mechanisms correspond to Satir’s communication stances of distracting or irrelevant, super-reasonable, placating, and blaming, each of which leaves out one or more of the elements in the interaction [11]. What would a congruent response to death anxiety look like? I believe that it would look exactly like the wounded healer role [12]. I include myself as a vulnerable and valuable human being, I include you as a vulnerable and valuable human being, and I am consciously aware of the context—that we are both subject to mortality, probably exactly what happened to Gabriel Conroy in Joyce’s story.

The Iceberg Metaphor

Virginia Satir’s iceberg metaphor says that we have layers below our immediate consciousness [13]. As shown in Fig. 9.1, below our actions there is a coping stance, feelings, feelings about feelings, perceptions,

Fig. 9.1 The iceberg metaphor



expectations, and finally at the deepest level longings. The coping stances correspond to being stuck at one level of the iceberg or in the distracting stance losing touch with our personal iceberg [14]. What then does congruence correspond to? Essentially it means being open to all levels of our own iceberg and most importantly to our deep longings and yearnings that provide the motor force and energy for everything above it. How do we get in touch with these longings? It is probably most easily done by directly facing our own mortality. That I believe is what happened to the pediatric emergency room physicians that I described at the start of this chapter. By contemplating their own survival for shorter and shorter periods, they got in touch with what was really important to them—their deep longings and yearnings. This was primarily for them, as in our experience it is for most people, the desire to express love and to receive love from those in their lives who are most important to them. Is this process also relevant for medical practice?

Longings and Expectations

One of the inevitable processes of living is that longings turn into expectations. I long for you to love me, and very quickly I turn that longing into an expectation that you will express your love in a particular way. I believe it is this fossilization of living longings and yearnings into rigid expectations that is at the heart of the distal defenses against death anxiety that are so destructive in relations between individuals, cultures and groups. In order to relate to each other in a healing way, we need to get below our expectations to the longings that unite us all; this is what happens in palliative care and it also needs to happen routinely in the practice of medicine. Yes, we will have expectations which are useful in the curing side of medicine, the white snake part of medical practice. And at the same time, we need to be able to put those expectations aside to get in touch with the healing side of medicine, the black snake. Death anxiety, when triggered below consciousness, drives us to concrete expectations, but when faced openly, allows us to contact our common longings that connect us more deeply to each other and this begins the process of healing.

Survival and Medical Practice

If you examine again Table 4.1 in Chap. 4, you will see on the left side of the table the goal is for patients to survive. This is perfectly normal and the primary reason that patients come to see us. This is the curative side of medicine. To move to the healing side of medicine, that goal needs to be complemented by a focus on growth which comes from letting go of some of our focus on survival in order to make space for healing. What we did not mention in Chap. 4 is that this means the patient facing his/her own death anxiety.

Physicians and other healthcare workers need to travel exactly the same journey—from an exclusive focus on their own survival, which will inevitably lead to distal defenses against death anxiety and distancing from their patients who will be treated as other, to facing their own inevitable deterioration and death, which will lead to an opening up that includes their patients as fellow vulnerable human beings, part of their own group. Like their patients, physicians need to personally embrace both sides of the medical dichotomy. This will take a profound shift in medical practice and in the training of physicians. I believe the benefits will be profound.

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Part II
Whole Person Care: Implications

Chapter 10

Whole Person Care for Medical Students

“If the wind were to stop for one second for us to catch hold of it, it would cease to be the wind.”

Allan W. Watts

But how can we teach whole person care to medical students? Three days ago, I completed the initial class of our mindful medical practice (MMP) course that is given to all second year medical students, in groups of 20 [1]. After teaching that class, I felt a surge of energy and hope that lasted for the rest of the day. This is the second year we have taught the course, and it was my sixth time teaching a group of 20. Each time I have the same reaction. What happened last Friday?

First I was surprised at how immediately open and interested the students were. In the first few classes I taught, my impression was that some students were on the fence, not sure what this had to do with the practice of medicine, not sure they wanted to find out. But not this time or the previous time. Word must have gotten around and they now came eager and already engaged.

We start the class by asking them what the class is about. In a very short time, they cover everything we wish to teach them. They say it is about mindfulness; being in the present moment; awareness; learning to create pauses in their busy lives; handling the bombardment of information from electronic media and other sources; relating to people in their lives on a deeper level, including colleagues, patients, and their fellow students; becoming aware not just of the external world but also of their inner experience; and learning to look after themselves so that they have something to give their patients. They are aware of all of this and believe that we can teach it to them. Luckily we don't have to in the sense of using our energy, experience, and knowledge to impart wisdom from on high. What we can do is to help them find what they need for themselves. It is exactly analogous to the process of healing. The person facilitating healing does not fix or cure the patient; he/she harnesses the resources the patient already has to move towards a sense of integrity and wholeness that is exactly what we attempt to do with our students.

SEES

We have found the acronym SEES helpful in facilitating this process of inner discovery in our students [2]. S stands for surprise. We like to start every class with something surprising, something that gets the students slightly out of their comfort zone. This can be very mild but needs to be enough to raise their adrenaline level a little. In the MMP class, we ask each student to tell the group what their first name means to them. This generally starts with some fairly light and superficial explanations, like my name means princess. But by the last few students, we are hearing about the meaning in their family or their culture, relationships to dead relatives, and so on. When everyone has spoken, we have taken the first step towards engagement in the class, which is the second letter in our acronym.

Engagement means primarily that the students are working harder than the instructor. In this first class, we achieve this by asking them to do the following: watch a short change blindness video; write down an experience of having missed something that later became obvious; list everything red in the room. Each time we use their reflections on what they have just experienced to elucidate the points that we wish them to learn. In the noticing red exercise, for instance, students notice the following: when they pay attention to something (e.g., red) that becomes their experience, the room becomes more red; when they are focused on red, they miss other things, e.g., blue or some of their colleagues leaving the room. No one person gets all the red in the room, so there are always things colleagues and others notice that one will miss—the importance of teams, listening to others in a team, and so on.

Emotional involvement is the second E in our acronym. This is perhaps what students are most afraid of. It can be achieved in a variety of ways. In the small group setting of our MMP course, one way we encourage this process is to have students share with each other in pairs before we open discussion to the larger group. It is much easier to share something that is emotionally charged with one person than with the whole group and much easier to share with the whole group after having rehearsed it with one person. We also set some ground rules to facilitate this process. We ask all students to agree to complete and double confidentiality with regard to anything personal shared in the class. The double confidentiality means that students will not share with anyone outside the class a personal detail that was shared (the first part), and they will not discuss with the person who did the sharing what came up, outside the class (the second part). Students are very willing to make this confidentiality commitment, and it creates an important element of safety that allows the class to function on a more open level.

Story is the second S in our acronym, and stories are used at all stages in our teaching to surprise, engage, and create emotional involvement. These

stories can come from students and/or the instructor. In this first class, the stories tend not to be very emotionally deep as we are just getting to know each other. But it is important that the instructor listens deeply and authentically to the stories that are told as we have found that listening in this way creates more stories and deeper stories as the process continues. Which brings me to the last exercise in the first class. It is an exercise in listening or not listening.

We pair up students with one of each pair given a task to complete on their cell phone and the other asked to tell their partner about something about which they are excited or passionate. The student with the cell phone is asked not to make eye contact, to focus on their cell phone, but to try at the same time to pick up what their partner is saying. The result? A clear and powerful experience of what it is like not to be listened to and for the person with the cell phone a realization of how often they listen (or don't listen) in this way in various relationships in their lives.

Reflection

We will deal later with the details of what we focus on in our teaching in the remainder of the MMP course and in our other teaching that covers all 4 years of medical school but for now let us answer the question “What is the essence of what we are teaching?” The answer is reflection. On a glass table in our offices in whole person care, we have a model of The Thinker by Auguste Rodin. The title “Thinker” was apparently given to the figure by the workers who cast the original bronze. For Rodin he represented Virgil in Dante’s Inferno gazing down at hell. Rodin originally called him the poet. I like that wide stretch between thinking and poetry because the kind of reflection we are teaching our students is equally wide and covers four different aspects of reflection [3].

Reflective Thinking

At the first level, reflection is about thinking. That is what most of us mean when we say we have been reflecting. We have been thinking about something or rethinking. We engage our students in this process continually. Someone says that our course is about mindfulness, and we ask “What do you mean by mindfulness?” We then take what they have said and perhaps use it to develop a definition of mindfulness. We might say, “Yes, mindfulness is about being present in the moment but in a particular way.” We

would then explore further, coming up with the addition that the kind of presence is nonjudgmental, either from the class or added by us. It is exactly the same kind of logical reasoning one might use to elucidate the timing of the heart sounds for students in cardiology or in helping them understand the calculation of glomerular filtration rate to assess kidney function. When we have mastered this process in a given area, it allows us to say we now understand glomerular filtration rate, or the production of the heart sounds, or mindfulness. This is the kind of understanding that gets tested in exams.

Reflective Doing

Donald Schon pointed out that there is more to professional practice whether it is banking or medicine than the logical solution of defined problems [4]. He gives a good example of a banker who realized after he signed a deal which made logical sense that he felt uneasy. What made him uneasy? Something about the rapidity with which the other person signed the agreement. His uneasiness subsequently proved to be justified. What is going on here? All professional practice occurs in a very complex context, and it is crucial to have an intuitive sense of that context in order to decide what problems need to be addressed, in what order, using what methods, and whether we might be missing something. I think of a patient with ovarian cancer who after surgery asked her doctor “Will I survive with this problem?” He responded, “Ask me again in two years.” It is an extreme example of completely missing the boat. He gave an honest and logically reasonable answer to her question. He would not really know until he saw her progress over the ensuing years. But the patient was looking for support, reassurance, probably a sense of caring, and accompaniment. She was afraid and needed someone to acknowledge her fear. She was devastated by the physician’s response and had still not forgotten it 10 years later.

We teach this reflective doing by getting students to begin to notice their own internal processes and the fallibility of their own perceptions. It is never possible to become omniscient, but by being aware of our limitations and the clues inevitably present within ourselves or in the environment, including coworkers and patients, we can do a much better job. At its most extreme, this might be taken as the poetic side of medical practice—the ability to listen to intuition that may be missed by the purely logical brain. And to do that effectively, a third kind of reflection is necessary.

Reflective Being

It is not just a question of having clear thoughts and intuitive sensitivity but we need to be present enough to bring the full force of our thinking and intuition to bear on the problem before us. In an excellent book, *Presence*, the authors point out that most of us move quickly from problem to preformed solution [5]. But to bring ourselves to bear fully, we need to slow down and give more space to the gap between problem and solution. This is the process of mindfulness [6]. We teach this to students both formally (meditation practice) and informally (how to be in the moment as you listen to a colleague or a patient). We also give them opportunities to experience the opposite of mindfulness which they easily recognize as very common in their lives, as for instance, when we ask them to both listen to a colleague *and* complete a task on their iPhone. It turns out that both effective thinking and effective doing in a professional context are dependent on this simple skill—to be fully present in the moment. Students easily recognize that this is the secret to both being better doctors for their patients *and* being reinvigorated rather than depleted by their medical practice.

Reflexivity

At the fourth level of reflection students often ask us about the problems with the system. Why do their superiors not always demonstrate or even encourage the skills that we are teaching? Why does the overall aim of the medical system sometimes seem more directed to efficiency than caring? We have two responses to these questions. The first is that we acknowledge the problems, but students will have to function in a system with these problems, at least for now. What we are trying to teach them are ways to think, do, and be that will make them more effective in any system. Our second response is that they are the future of medicine, and we hope to see the system change as they begin to have a bigger say in how it works. To do that effectively, they will need to become more reflexive. Reflexivity is the ability to bring a nonjudgmental awareness to the system in which we work, to be willing to express ourselves, to have the courage to resist how things are, and to stand for something better. We find that students are both intimidated by this possibility and excited by it. As Samuel Shem points out, this may be one of the most important characteristics and duties of a medical professional—not simply working within the system but changing the system within which we work [7].

The Whole Person Care Curriculum

We teach whole person care in a progressive way in all 4 years of the medical curriculum using large group sessions, the class split in two, small group intensive experiential classes, panel discussions, essay readings, and work in the Simulation Centre. Whether in large or small groups and whatever the format, this material is part of the core teaching of *all* medical students at McGill University.

The First Year: Inspiration

In our first year of teaching which consists of five large group interactive lectures and one session where the class is split in two, we attempt to harness and grow the altruistic longing that medical students have to make a difference. This may sometimes be buried but is always there and can be nurtured and stimulated. On their first day we start with the first lecture in which we present physicianship [8], which is the combination of healing (the ultimate purpose of medicine) and professionalism (how medicine is organized and structured within society). From whole person care, we teach the healing side, illustrating our teaching with a powerful and moving clinical story from our recent experience. The primary aim is to place healing at the center of medical practice in students' minds and to illustrate what is possible in clinical care.

This first lecture is followed by four further large group sessions as follows:

- Healing relationships in medicine in which we clarify the difference between curing and healing and the very different attributes, attitudes, and skills that they call on from both patients and physicians [9]. The take-away message is that we need both, which is whole person care.
- Suffering and meaning in medicine in which we show a film about Viktor Frankl called "The Choice is Yours" [10] and discuss it with the class. The main point is to stress the importance of meaning in the healing process and to have students experience this by proxy in the life of Viktor Frankl.
- Healing in cardiology in which we introduce a patient either in person or by video to sensitize students to the patient's experience. They begin to see patients as whole persons and not just as carriers of a disease. This both humbles students and clarifies the importance of the work that they will do for these vulnerable human beings.

- Healing in nephrology in which we attempt to give students an experiential sense of what it is like to be a patient being treated with a complex medical intervention, in this case hemodialysis treatment. We adopt various maneuvers including having some students follow a hemodialysis diet for 24 h (includes limited fluid and potassium intake) and report to the class and having all students sit with one hand taped down as if with a fistula needle in place and watch a detailed video of a nurse putting a patient on hemodialysis. Their experience is then discussed with professionals and patients from one of our hemodialysis units. The aim is to get them as close as possible to the experience of what is like to be a patient.

In the students' final session of their first year, immediately before they head off on vacation, we split the class in two, and with students divided into tables of ten, we review the challenges of the past year and their perceptions of the year ahead. Each table lists their main points and pins them on the wall where they are read by all students circulating during a halfway break. After the break, one student from each table presents their list, possibly modified by seeing the other lists, and we discuss the issues raised with the whole group. The purpose here is to identify approaches that helped or will help to deal with difficulties and challenges. It is at this point that we introduce the idea of mindfulness and how moment-to-moment nonjudgmental awareness can be useful in the challenges that they have identified and in their work as physicians. We let them know that we will be explicitly teaching this approach in second year in a mindful medical practice (MMP) 7-week course immediately prior to clerkship. This serves two functions. We acknowledge students' past and likely future struggles and create anticipation for a course that will help with those challenges.

The Second Year: Preparation

In the 6 months immediately prior to clerkship, we teach a 7-week course (MMP) to all students in groups of 20 [1]. Each Friday morning class of 2 h has a theme, core concepts, and specific learning objectives and is conducted as a deliberately interactive and experiential session. We move between short periods of guided awareness, group discussions, dyad discussions, whole-class exercises, short videos, role plays, and narrative exercises, all aimed at inculcating the core way of being that we believe is central to the practice of whole person care: mindful clinical congruence. The titles of the individual sessions are as follows: (1) Attention and Awareness, (2) Congruent Communication, (3) Awareness and Decision Making, (4) Clinical

Congruence, (5) Building Resilience, (6) Being with Suffering, and (7) Mindful Congruent Practice in Clerkship and Beyond. Students are evaluated by attendance, active participation, multiple choice questions, and a 1250-word essay summarizing their experience.

We have found this course an absolute joy to teach. Contrary to our initial expectations in teaching these kinds of intense experiential sessions to the entire class, we have encountered minimal resistance that has usually faded away in the few who exhibit it after the second or third class. Students see the relevance and importance of what we are teaching both for their effectiveness as physicians and for their own well-being. We are presumably aided by students' anxiety in anticipation of clerkship and their desire to learn anything that might help them in what they perceive as a daunting and challenging future experience.

Of course, teaching these classes takes prior training on the part of instructors. All of our instructors have taken mindfulness training outside McGill and have a regular meditation practice. Before we started teaching these classes, we rehearsed each of them with the faculty who would teach the classes so that everyone had a moment-to-moment sense of how each session would go. There is a detailed plan for each class that indicates what should be happening at 5–10 min intervals. Before a new instructor begins teaching these classes solo, besides the requirement of prior training and regular meditation practice, he/she sits in for 14 classes (7×2) during which time he/she both observes and starts teaching part of the classes under the supervision of the instructor. This is both time consuming and demanding but more than rewarded by the success and impact of these classes. Since we do not believe it is possible to teach this course successfully without this intense instruction, we plan to write a detailed instruction manual that will appear as a separate publication.

The Third Year: Application

The center piece of our teaching in the third year is a session at the Simulation Centre in which we confront students with difficult interactions with patients or other professionals [1]. The idea is to recreate situations that may occur in the clinical setting which can catch students off balance.

This is step one in the process. Students then either succeed or fail to regain their balance in these short scenarios (5 min) which are then debriefed with two other students and a faculty mentor. After every student has participated in a scenario and has been debriefed, we then assemble in a larger group to review what has happened and what has been learned in the different groups.

These sessions are conducted in groups of 30 students and run for 4 h from the time the faculty arrive to the completion of the session. There are five stages in the process:

1. New faculty are briefed on what will happen and what we are trying to teach (30 min).
2. All faculty and students attend a large pre-brief that clarifies the process and rules for participation and gives some of the context for this teaching (30 min).
3. Groups of three students and one faculty member enact three scenarios with simulated patients or simulated healthcare professionals playing the parts. One student participates in each scenario that is then debriefed (90 min).
4. Large group debrief in which a facilitator reviews what happened and how students responded to each of the scenarios. This is a very interactive session with students coming up to the front of the class to revisit their response to the particular clinical interaction with a view to elucidating for themselves and for the rest of the class what they have learned, what they might change, and what worked well. This also becomes an opportunity for faculty to comment from their clinical wisdom and experience (60 min).
5. Faculty debrief in which faculty, after the students have departed, reflect on the session, what worked, and what should be modified. This is also an opportunity to raise concerns about the safety of particular students who appear to be vulnerable and who may need follow-up (30 min).

What are we teaching in these sessions? The objective is to give students the opportunity to apply in a safe environment the mindful clinical congruence that they have learned in the second year MMP class. This message is brought home at various stages but particularly in the large group debrief (stage 4) when the Satir communication stances are reviewed and the meaning and relevance of mindfulness are revisited. We are often surprised at how easily students remember the material from the previous year and see its relevance in this context. We administer a before and after questionnaire to assess the students' perception of the impact of these sessions on their confidence, skills, and attitudes [1].

In third year we also have the students for two recall days in which the whole class comes back from their clinical clerkship to the classroom for two full days. In the first of these days, we conduct two panel discussions, one with patients and one with doctors. The panels respond to a series of questions on their experience (How did they become a patient or a doctor? What was their best experience or worst experience? What have they learned that students should know?). Students then follow up with their own questions for the panel. This is an explicit opportunity for students to step back

from their intense clinical experience and reflect. We are particularly interested in reflection that broadens the students' perspective, hence hearing directly from patients and from physicians with extensive clinical experience. We also highlight the relevance of healing because students can easily become distracted from its importance in the busyness of clerkship.

In the second recall day, we explicitly ask students to reflect on healing as they see it in day-to-day clinical practice by asking them to write an essay on a topic related to healing, as they have personally experienced it in clerkship. These essays are reviewed and commented on by faculty, and four essays are read in front of the class and discussed by a panel consisting of four experts in ethics, healing, professionalism, and physicianship. The essays we choose are excellent and thought-provoking. The themes of each essay are uncovered by the panel, and the students then participate in an open and vigorous discussion of healing in medicine. We increasingly notice that for our students, healing is an integral, essential, and explicit part of medical practice, and this view is re-enforced and enriched by this reflective recall day.

The Fourth Year: Transition

This is an aspect of our whole person care curriculum that is still in the development stage. Currently we teach a 90-min session in which we review for students the place of healing in medicine and how this will be relevant as they move into the next phase of their careers. Our plan is to develop a recall day in which students will be divided into smaller groups and be given an opportunity to participate in a more advanced version of the experiential learning that they experienced in the MMP course in second year. This is another transition point in their careers, and we believe, just as in second year, the anxiety about entering a new and challenging phase will make students particularly open to teaching that helps them nurture their own internal resources with a view to providing better care to their patients and taking better care of themselves.

Identity as a Healer

It should be clear from what we have described that we are not simply trying to produce doctors with standardized knowledge, skills, and attitudes. This would be attempting in Allan Watts' words quoted at the

beginning of the chapter to stop the wind. We wish our students to be more than knowledgeable and skilled technicians who are expert at the job of diagnosis and cure, although they certainly need to master that knowledge and those skills. They are also developing a sense of themselves and their role as a whole person who facilitates healing. This does not happen quickly. It involves deep change that we believe can only be produced by experiential learning involving the entire process of medical school training [2]. It is almost certainly not a linear phenomenon and involves periods of transition and growth alternating with times of stabilization and consolidation. The hidden curriculum [11] is as important as the formally taught curriculum. We are facilitating the development within the student of a new identity as a healer that we will explore in more depth in the chapter that follows.

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Chapter 11

Identity Formation as a Physician

“At times I felt like a thief because I heard words, saw people and places—and used it all in my writing ... There was something deeper going on, though—the force of those encounters. I was put off guard again and again, and the result was—well a descent into myself.”

William Carlos Williams

My most passionate and clear sense of identity is in being Irish. I wonder what that says about the process of identity formation that may be relevant to the topic of this chapter. Where did my Irish identity come from, why does it feel so deep, and what are the factors that produced that sense of being Irish?

It began in school with history lessons. The pattern became very familiar. We Irish, who were always the good guys, were invaded by foreigners, particularly the English. Although we were braver and better and won some battles, we always lost in the end. I remember a description of one battle when we were doing very well, but at the end of the day because of where the two armies were placed, the sun shone in our eyes, and we could not see to fire. We lost again. I remember longing for a victory, for a little luck, for things to turn out our way. Even as I remember that long distant battle, my heart aches with the longing for things to work out for us.

What am I talking about here? It has nothing specific to do with being Irish because whatever one's national or ethnic origins, something deep in us needs to be touched in the process of identification. It is the power of longing. That is why Virginia Satir puts longing at the base and origin of the iceberg metaphor [1]. It is that longing and passion that we need to tap if we want our students, residents, and physicians not just to act like doctors but to feel in their very bones that this is who they are, what they are meant to be doing.

So before all else, the question for me becomes how do we tap this source of energy and power. I would say that there are two answers: mythology and personal history. It was the power of mythology that I experienced when I learned Irish history. Not that there was not some factual truth in the history that I learned, but the framing of us, the Irish, as heroes valiantly battling

overwhelming forces was mythology in the best sense. It tapped the same energy that Joseph Campbell identifies as universal across cultures in *The Hero with a Thousand Faces* [2]. I learned a particularly Irish version of it in which the hero battled valiantly but lost the battle, and I wonder if there is not a lesson in that too, because losing battles leaves the longing and yearning unsatisfied as in reality our deepest longings are no matter how many successes we have had. It is that unmet longing that I would like to see tapped in our medical students.

In personal history we want to find out what unanswered personal longing led this person to become a physician. In my own case, I believe it was my mother. As long as I knew her, my mother was sick. She had extremely high blood pressure that she and certainly I considered life-threatening. She was admitted to hospital a number of times for treatment, and the pills she took daily had severe side effects, primarily extreme postural hypotension. As a kid of 9 or 10, I remember distinctly both deciding I would become a doctor and thinking how sad it was that my mother would never see this happen because she would be dead long beforehand. I pictured very clearly that I would walk into a room one day and find her dead. That was just the way it would be, but I would become a doctor.

My assessment of my mother's prognosis turned out to be far too pessimistic. She did see me qualify and practice as a doctor. At one stage when she visited us in New Haven (I was a clinical scholar at Yale), she became very ill with acute on chronic bronchitis. I treated her with high-dose corticosteroids for her acute asthmatic symptoms and got her well enough to go home with my dad's support. It would not be what we would advise our students or residents to do (too much responsibility), but nothing I have done in medicine was more satisfying. Of course, because it was the longing to help my mother that got me into medicine in the first place.

Medical Mythology

In a world dominated by scientific understanding and evidence-based practice, is there room for stories that touch the soul, the deep longings and yearnings that motivate us—a mythology for medicine? Michael Kearney and others have harnessed Greek mythology [3] but those stories relate to a world very different from ours. What I would like is a mythology that speaks more directly to us and our everyday experience in medical practice. And yet it would be a mythology; stories with a kind of truth that speaks to our longings, not another guideline or best practice.

The first mythological story that I heard in medical school concerned a physician who was revered as an expert diagnostician. When asked what the

basis for his expertise was, he said that once he sat down by the patient's bedside, he didn't get up until he had made the diagnosis. I love that story. Of course it cannot be literally true. I picture this doctor sitting for days with the nurses, or nuns as they would have been, visiting him with meals, "Are you OK doctor, anything else you want?" "No I am just going to sit here till I have gotten to the bottom of this." What about the other patients he needed to see? What about efficiency? And yet there is an element of truth in that story that touches me deeply. How often do we practice superficially, more focused on moving on from this patient with an answer, whether it is the right answer or not? What if we stopped ourselves and committed to staying there until something real and useful, and possibly unexpected, emerged? What a satisfying and rewarding practice that would be for us and our patients. What if that was part of our identification as a physician?

I never met the expert diagnostician described above and perhaps it is just as well. We need heroes who can represent the best of our own possibilities, but they probably need to be distant or dead where mystery is stronger and hero worship can be untainted by contact. When Lincoln died it was remarked "Now he belongs to the ages." [4] We need medical figures for the ages.

I am not sure how difficult it would be to assemble such a pantheon. I can think of some offhand who should probably be part of that list: William Osler, the Mayo brothers, Willem Kolff, Cicely Saunders, Viktor Frankl, and possibly Oliver Sacks. Should the Fat Man from *The House of God* [5] be on that list? Each of these physicians has an inspiring story that touches the soul of medicine. Students need to hear these stories as they embark on their own mythological journey. Instead of being stuck in the mire of daily grind and difficulty that medical practice can be, they need a mechanism to rise above all that and when faced with a new challenge to ask themselves what would William Osler have done, or Cicely Saunders? The identity as a physician will be lived out in a day-to-day experience, but it will be particularly tested when faced with overwhelming difficulties. In these testing situations, our students and physicians need something to fall back on that will allow them to see a larger perspective and live true to their values as physicians. The more difficult are the times, the more they will need a mythology to tap their longings and provide the energy necessary to stay true to their vision.

Personal Longings

How are we going to tap students' personal longings and yearnings to make them better doctors? This will require a depth of relationship with themselves and possibly with a mentor that is not easily reached in medical school. At McGill University we currently have a mentorship program in

which every six students has a faculty mentor throughout all 4 years of medical school [6]. The students and mentor meet from four to eight times per year and discuss issues related to their professional development. But could deep yearnings be shared in a group of this size? I am not sure. The degree of trust required might be difficult to achieve.

But perhaps the specific details of the longings do not need to be identified and discussed. What is needed, I believe, is to make space for the personal longings that students bring to medical school. It is a bit like facilitating healing in a patient. As a facilitator I don't need to know exactly what produces the energy for your healing. It may always to some extent remain a mystery. And yet making a space for the individuality of that mysterious process may be the difference between burnout and an energized and satisfying practice.

Are there generic ways of touching an individual's longings? Most religions have times of deprivation and fasting prior to a pivotal feast or celebration. People from the North American First Nations have versions of the vision quest [7], a time of fasting and solitude at key transitions in a person's life. The purpose of these intense experiences is, I believe, to put people in touch with a very immediate longing for food, water, or other people as a way of touching deeper longings that give meaning to a person's life. This is a very old technology of human growth and development that perhaps we should revisit in medical school. Could this be done at graduation or at key points in the course of medical school? Certainly there is already significant hardship and deprivation in medical training and practice. Could these experiences be harnessed in this process?

Expectations

How are we to retain and even develop further the aspirations that students bring to medical school in the face of the multiple expectations that come with being a medical student and a doctor? There are expectations on the knowledge they must master, the skills they must acquire, the attitudes and values they must espouse, and now with the focus on identity, the way they must be as students and doctors. And these expectations come not just from patients—the immediate and central relationship in their work—but from other doctors and healthcare workers, their superiors, their institutions, governments, and the general public. How can any one individual make all of those people happy or at least satisfied? And increasingly we are finding ways to measure compliance with expectations and are bringing to bear disciplinary measures and punitive consequences for those who fail to meet the

particular standard. We are even beginning to think about ways to measure professional identity formation and ways of being [8] so that we can check whether these standards are also being met.

There has to be a better way to think about the formation of a doctor. I would characterize the approach based on imposing expectations and measuring compliance as one based on a machine metaphor [9, p. 13–14]. We are trying to develop a machine that responds in a predictable and satisfactory way to different problems and contingences. We would like to standardize this process so that everyone follows “best practice.” Doesn’t every patient deserve the same treatment and the best treatment? Who would argue with that? But suppose we changed our metaphor from developing a machine to that of transforming living human beings so that the central aspect of their job is not what they know, what they do, what they say in a particular situation but how they relate [10]. This is the message that I take from the proposal that medical education is essentially a process of socialization [11], a process in which you experience a new set of relationships and learn how to function effectively in that new context. And for proponents of whole person care, this is particularly cogent since it is the healing *relationship* with the patient that we believe is central to our work as physicians [12]. And we believe that the healing aspect of this relationship is what needs to be brought to all of the other relationships in a doctor’s life—with family members of patients, with colleagues and co-workers, with institutions, with the government, and with the general public.

Role Models and Leadership

How do we teach that to students? Not by standards, not by measurement, not by practice guidelines, and not by evaluation but primarily by role modeling and leadership in real work situations. There is no other way that students can learn the subtleties, the possibilities, or the feasibility of functioning effectively in an often exceedingly complex and unpredictable medical milieu in a way that is satisfying and helpful for both patients, the physicians themselves, and other people with whom they relate. And even the title role model is questionable because it suggests a template or blueprint that we can follow. Sometimes clinical contexts are so complex that is difficult or impossible to imagine an appropriate algorithm for the specific circumstances.

Let me give you an example from my own experience early in residency. I had recently arrived in Montreal and was starting a rotation in cardiology. It was a consultation service with a very energetic and opinionated staff per-

son, a senior cardiology fellow, and a few residents including myself. The Fellow was the person who showed us how to make everything work. Early on I realized that although our staff person had a reputation in research and had strong ideas, he was the most wrongheaded physician I had ever met. He sometimes (often enough) suggested approaches that would have been counterproductive and even disastrous for the patient. So the Fellow had a very complex job: to see and relate to all the patients that needed to be cared for, to keep us all motivated and learning, and to protect the patients and us from the staff person. And he carried it all off with aplomb. How did he manage that?

First, he could size up a medical problem quickly, had a clear sense of what should be done, knew the rationale, and could explain it well both to us and our staff person. This meant that we learned a lot, and he could modify suggestions that would not have worked. Second, he managed the relationship with the staff person with humor and graciousness. As you can imagine, there was significant tension in this relationship, and the staff person was continually wanting to get ahead of the Fellow and to have his ideas followed. The Fellow never confronted this head on, which would never have worked; he simply made sure he was always there first. One famous example was when a patient of ours was scheduled to come out of the operating room after a valve replacement and our staff person went to the recovery room to await the patient's arrival. He was very surprised when the patient arrived accompanied by the anesthetist and the Fellow who was bagging the patient and discussing with the anesthetist what should happen next.

The Fellow was so much himself and at the same time he related to all of us—patients, residents, and even our staff person—in a way that brought out unexpected growth and development. To take a minor example, once the Fellow asked me about the vector of the R wave on an EKG. It was not something I had thought about before, but I reached back to a barely remembered understanding of vectors from high school. The vector did not seem to be going anywhere, and it struck me it must be going straight up vertically. He looked at me with appreciation and said “I guess you had no problem with math at school.” I was never more encouraged and empowered in my life. I guess the word for this process is leadership that called on those around him to excel and exceed what they thought possible for themselves. In the film “The Choice is Yours,” [13] Viktor Frankl says, quoting Goethe, that if you take man as he is, you underestimate him, but if you take man as he could be, you find out his true abilities. That is the kind of leadership that our students need to experience so that they can bring the same leadership to their patients and colleagues.

Transitions

One of the mantras of the professional identity literature is that periods of transition are extremely important [14]. I would agree because these are times for more rapid growth and development. Whether it is starting medical school, beginning clerkship, or starting a residency, these transitions represent unusual opportunities for change and transformation. I am very much aware that the distinction that we make between curing and healing in patient care applies equally here. If we adopt a curative approach, the will, energy, and resources come from the faculty and those teaching and organizing the curriculum. The intention is to produce or impose change at a pace and in a way dictated by us.

If on the other hand we adopt a healing approach, the energy comes from the students, and the change and/or transformation will occur at a pace dictated by each student. It is exactly similar to the process of healing and growth in patients. Each patient facing the transition from active chemotherapy for their cancer to palliative care faces a huge transition in their lives. The support and help that they receive from their caregivers is crucial, but the pace of growth and change will be unique to each patient. It is neither linear nor completely predictable. The skill on the part of the healthcare professional will consist more in listening than instructing, supporting rather than imposing. Attempts to force the issue will either lead to wounding and resistance or to superficial change and compliance that does not go very deep and does not involve real change or growth.

We also need to harness students' anxiety in the face of a new transition to provide energy for change. They may be more open to listening and learning new skills and ways of being that they believe will be helpful, as we have found in our teaching of mindful medical practice in the lead up to clerkship.

Mindful Clinical Congruence

But what central identity are we hoping to promote? There are many on offer. The CanMEDS roles [15] describe a whole range of possible roles any one of which could become an identity. But is there a core identity that supersedes or combines all of these? The identity that we are hoping to promote in our students and residents is mindful clinical congruence [12], which combines mindfulness (moment-to-moment presence) and congruence (present to self, other, and context) in a clinical context.

This allows every student to be different and yet share the ability to bring their full selves to the practice of medicine, even in very stressful and pressured situations. We believe that this is essential if students are to function not merely as technical curers of disease but as physicians who can promote healing in their patients. It is probably also the secret to the students' own long-term well-being in the practice of medicine. The skills and ways of being that we are teaching our students are aimed not at specific outcomes or actions but at developing an identity that dictates how they should relate to their patients and colleagues.

External and Internal Identification

We wish students to identify externally with the work of physicians as a group—this is what physicians do and how they relate to society. We also need students to identify internally with a way of being that allows them to bring their authentic selves to the practice of medicine. They need both to fit an external world *and* to function independently within that framework. Why this focus on independence? There are two answers. First, some of what students are exposed to is destructive: lack of attention to the human needs of their patients, their colleagues, and themselves; lack of empathy and sometimes abuse of patients, students, and others; and a system that can be very demanding, does not give physicians a sense of control, and fails to give appropriate acknowledgment. These are the kinds of factors that lead to burnout [16, p. 116–117], which is why we wish to give our students an identity that can flourish independently within that milieu.

There is a second reason. The title physician or doctor carries weight in most societies, and this is likely to boost students' self-esteem. This is probably inevitable, but we would like to limit this effect because self-esteem based on group membership almost inevitably means devaluing those who are not members of the group, including co-workers, but most importantly patients [17]. This is not what we would want, particularly on the healing side of the medical dichotomy, because the process of student growth and development should exactly follow the divergence between curing and healing in medicine. We need the students to develop a sense of themselves that has both a shared identity and a sense of their own unique gifts. On the healing side, we would like the medical school to be more similar to Jung's individuation [18] or Bowen's differentiation [19] where students learn more about themselves as persons and base their self-esteem on their own unique value as persons regardless of their power or specific role within the context of care.

Passion

What of the passionate commitment that I spoke of in the beginning of this chapter that in my case was associated with being Irish? Is this kind of passion possible in a context that combines group identification with individual growth and development? I believe that it is not only possible but that the two aspects potentiate each other. To master a body of knowledge and clinical expertise relevant to medical practice or a particular aspect of medical practice gives medical students and doctors a different starting point for relating to patients and promoting healing than say a nurse, a psychologist, or another health professional with a different background. The background is essential because it ties the student to a whole world of medical knowledge and experience that is both worldwide in its scope and based on a long history of research, practice, and tradition. It is a solid starting point from which the individual student has the opening to develop his/her own ability as a healer. The passion comes, I believe, from that potent combination of group support and identification and the permission for individual self-expression and creativity that the practice of medicine makes possible. Perhaps at its best medical practice is not too different from being an Irish poet like W. B. Yeats where being Irish *and* a poet [20, p. 27] are both essential elements in the potent and passionate alchemy.

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Chapter 12

Wellness, Burnout, and Compassion Fatigue

“Happiness is neither virtue nor pleasure, nor this thing nor that but simply growth. We are happy when we are growing.”

W.B. Yeats

It was summer in Montreal, and I was looking forward to my dad’s visit and a vacation in the country, which was why I made my escape down Peel Street, past the part of town with which I was familiar, along streets with industrial buildings in search of a fishing shop and a lure, a fishing lure that would somehow awaken my old love of streams, lakes, and fish and that would ease the deadness and burden of clinical care.

I had just left the intensive care unit where I had seen an obese woman in her 30s with diabetes, wounds that were not healing following surgery, and acute renal failure for which we were dialyzing her. I am afraid I could see no hope in her situation. She looked to me like she would never recover and get out of that bed. Her legs were edematous and immobile. It was painful to speak with her, and I was left with a heavy feeling from which I was trying to escape. Was I well? Definitely not. Was this burnout or compassion fatigue, depression, or something else? Was the fishing lure a good intervention? Probably not, but I had no idea what else I might do.

Is this kind of feeling rare in medical practice? In my experience from talking with other physicians, it is relatively common. The statistics on burnout confirm that impression. Rates of burnout in physicians are reported to be between 25% and 60% [1].

Burnout

Burnout is characterized by emotional exhaustion, lack of a sense of personal accomplishment, and depersonalization [2]. That day in Montreal I was clearly exhibiting all three. It seems to me looking back that the

symptoms came in a specific order. First I had a sense that what I was doing was not working. It was not just this patient in the ICU, but the patients that I had seen earlier that day, that week, and that month. Almost all of them had unfixable problems, and we were just keeping them alive so that they could suffer more—the meaning that I gave their situation, not necessarily the truth. Then came emotional exhaustion. It is emotionally exhausting to continue to persist in doing what deep in your heart you believe is not working and will not work. It is even harder when you don't see a reasonable alternative. And so I took the only avenue that I thought could distance myself from my pain—depersonalization. I continued going through the motions treating the next patient and the next patient as if they and I were machines, not people. I could continue to do this until I got to the end of the month when I could go on holiday and get away from all of this. In Virginia Satir's terms, I adopted the irrelevant stance [3], and that fishing lure was a way of getting an installment of that vacation today and not waiting for my real vacation to begin.

Whole Person Care and Burnout

Could another way of understanding what my job was in medicine have made a difference to my experience? Suppose I had seen my job as not simply fixing or curing medical problems but also facilitating healing in the persons with these problems. How would these have looked in the woman I had just left in the ICU?

That day in the ICU I stood at the patient's bedside. I asked her how she was, but without any real interest. I wanted as little personal contact as possible, as contact would only have increased my own feeling of dread and discomfort. I stuck to the medical script mainly focusing on the plans for the next dialysis. Suppose I had instead sat down at her bedside. I might have allowed myself to be really curious and caring about how she was doing. Were there questions she had or something that she felt would help her? Or perhaps she might want to talk about herself in some other way with me present, listening and attentive. Would this have made a difference to her? Almost certainly. But more relevantly for this chapter, it would also have made a difference to me. I believe I could have left her bedside with a sense that I had made a difference (personal accomplishment), was enriched by this human contact (emotionally recharged rather than exhausted), and was back in touch with myself and her as a vulnerable human person (personalized not depersonalized). So, if it is such a good idea, why didn't I, and why don't we do it more often?

Avoid the Wounded Place

Strange to say but the problem is the limited medical mandate that we apply to our patients and ourselves. From this perspective, the situation they and we are in right now is not acceptable. Our mandate is to fix the problem and get to a better place. My patient's renal failure needed to resolve, her wounds needed to heal, and we needed to get her up and walking and home. I needed to get through this moment, this day, and this week, until I could go home or go on holiday. And what about the time between then and now—time with less than no value because it involved suffering?

The alternative is to turn towards the wounded space and experience the value that exists here and now [4], as I could have done in the ICU that day. Is it possible? Not only possible but absolutely necessary if we are to experience the real rewards and value that are in our work. It is that value and not any self-protection that will provide what we need to grow in our work and be sustained and nurtured rather than depleted and burned out. It is the paradox at the heart of medical practice.

Another way of framing the above is that we need to move from a practice solely focused on the white snake of curing to include a practice and a presence also focused on the black snake of healing. And the great difference between the white snake and the black snake is that with the white snake only the patient experiences the fixing or curing, although there may be some justified satisfaction on the part of the practitioner. With the black snake, if the patient is experiencing healing and a move towards integrity and wholeness, so is the clinician [5]. It is that exchange of healing energy which is the antidote to burnout.

Resolution

So how did I resolve my situation that summer in Montreal? Did the fishing lure, my dad's visit, or the holiday help? Sadly to say, no! I did find the lure, my dad did visit, I did go fishing, and I did survive. But I remained in survival mode. I was able to continue to function reasonably well but would again become depleted at the end of each month on nephrology service. The spark that had become a flame as a nephrology resident had dwindled to a flicker.

The resolution for me came in a switch to palliative care, a very definite move towards the wounded place. In palliative care I found a commitment to healing. Our patients were dying. We would fix what could be fixed,

control symptoms as expertly as we could, and at the same time support our patients in a healing journey. It was a complete shift in emphasis and conceptualization of what medicine is about, and it completely resolved the kind of feelings I had experienced for so long in nephrology.

Teamwork

What changed and what made such a big difference? Yes the conceptualization of care had altered to include healing. But I could not have done that on my own. I have inferred that if I had changed my attitude and approach to my patient in the ICU I would have been energized and repleted. Yes, but without support to follow that path I believe I would have failed. I was already trying to move in that direction, including publishing a book of stories of patients with kidney failure [6], but it was not sufficient. I needed a team who shared and supported the philosophy of whole person care.

Michael Kearney and others have suggested that burnout has more to do with the system in which we work than the suffering of our patients [7]. I believe that it is both. I believe that it starts with our patients' suffering. If we work in a system that turns away from that suffering and encourages us to do the same, we cannot avoid a feeling of failure and hopelessness because our patients continue to suffer, as we do, and we cannot avoid being aware of this reality no matter how determined our denial. In palliative care I found a team that turned towards patients' suffering and the potential for healing that accompanied that suffering. This was an everyday concern from all parts of the team including nursing staff, physicians, and allied health personnel. It was a constant topic of interaction and conversation, a subject discussed at formal rounds and raised continuously at support meetings. And it was not just our patients' suffering of which we became aware but our own suffering, which like our patients was held, helped, and sometimes transformed by the sharing and support of the group. It is that philosophy and that kind of support and interaction that whole person care hopes to bring to the rest of medicine.

Let me give you from palliative care a counter example to the patient I described in the ICU. She was a woman in her 40s, with two children, a boy and a girl, who were between 10 and 12. She had metastatic stomach cancer causing jaundice, nausea, vomiting, and severe weight loss. She was clearly dying, which she knew, and we arranged a family meeting so that she could say goodbye to her children. The meeting was held in her room and was attended by her husband and two children, two physicians, two nurses, including the assistant head nurse, and a psychologist. I led the meeting

standing at the head of the patient's bed, and the main focus was this very brave woman's conversation with her equally brave children. They asked some questions, she spoke honestly, and we finished that meeting with a sense that she had said goodbye. It was extremely sad, very moving, and surprisingly not depleting but, if anything, energizing. We had faced what needed to be faced and had helped this patient and this family move forward in a healing process that might take years (life times?) to resolve. But a start had been made.

Compassion Fatigue and Boundaries

It might be thought that our care of this family could easily have led to compassion fatigue. Certainly our compassion was completely engaged by this woman and her children. My colleague, the other physician at the meeting, said it took all of his self-control to avoid sobbing openly during the meeting. And yet it was not fatigue that we experienced. The reason I believe is that we had sufficient boundaries to empathize with this family's suffering and yet not confuse our suffering with theirs. We were practicing what has been called exquisite empathy [8]. Rather than the distancing and turning away from suffering, as I had learned in nephrology, we had turned towards our patient's suffering with compassion and clear boundaries so that we could participate in a healing journey that was not only good for our patient but was the key to our own healing, growth, and repletion. Burnout and compassion fatigue are major problems in medicine, and to resolve them we will need teams and individuals that have learned to practice a medicine that employs our full selves in our work, relating to each other as full vulnerable human beings and treating our patients in the same way.

Wellness

In our quest for wellness through meditation, exercise, diet, work-life balance, vacation, and protecting ourselves against fatigue, overwork, burnout, and compassion fatigue, we may lose sight of the fact that reasonable as all of these measures are they have little to do with wellness. They are good survival strategies and should not be undervalued for that reason. But they have only a very limited effect on subjective well-being.

Yeats' happiness, quoted at the beginning of this chapter, is the kind of deep subjective well-being that we need to find in our work and bring to our

patients. It is the phenomenon that Balfour Mount and Michael Kearney discovered in their dying patients whose subjective well-being was increasing at the same time that their health was deteriorating. It is this well-being that the benefits of whole person care can bring to medical practice. I believe that Yeats is correct that the key is growth, not simply growth to a fixed point of competency in training but continued growth throughout our careers as we learn more about ourselves and how to practice medicine. This will take quite a different model of medical identity and functioning. Instead of simply asking ourselves how competent we have been in the past year or how good a job we have done, we need to ask ourselves how much we have grown, because in the final analysis the underlying key to wellness and protection against burnout is not avoidance of wounding, or self-care, but change and growth.

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Chapter 13

Narratives in Medicine

“For sale: baby shoes, never worn.”

Attributed to Ernest Hemingway

As Hemingway’s story above suggests even with very few details, stories can convey a lot. And yet they can often be overlooked or dismissed, to the detriment of the therapeutic interaction. Somewhere in my 40s, I was having a midlife crisis and seeing a therapist. She asked me to tell her about my mother. I began to do just that including a description of my mother’s death which had been sudden and a little mysterious. She asked me what I thought had really happened. I told her my interpretation of events. Soon after that she announced that she had heard my “stories” and we would now move to more important concerns. The implication was that the stories were merely a prelude or introduction and we would now move to serious issues and therapy. I felt cut off, devalued, and even betrayed. I had shared very intimate stories with this person and was expecting some engagement with me and my stories, which felt like a part of my bared soul. Not surprisingly, although I persisted with the therapy for a while, I never recovered from that initial shock or benefited from the therapy. I suspect that my underlying anger against this woman prevented *me* from engaging in the therapeutic process.

Illness Narratives

Arthur Kleinman points out that western medicine with its focus on disease increasingly devalues and ignores the illness stories of patients [1]. Kleinman points out that one of our most potent tools in relieving suffering is listening to and witnessing our patients’ stories. He tells a wonderful story of his experience as a medical student caring for a 7-year-old girl suffering from

extensive burns. The patient had debridement of her burn wounds in a whirlpool path on a regular basis. The process was excruciatingly painful and the young girl pleaded to avoid it. Kleinman's job was to hold her hand and attempt to comfort her. He spoke to her about various things, her home, her family, and so on, in an attempt to distract her from her pain. This did not appear to be very effective. At some point he asked her what it was like to be so badly burned and to experience the painful ritual day after day. According to Kleinman she began to do just that with remarkable effects on her level of comfort. She stopped resisting and screaming and began to engage more and more with him and to experience less pain and suffering with the daily debridement treatments. It was a therapeutic breakthrough.

What worked in Kleinman's interaction with this patient? Clearly he was not the expert in illness narratives that he later became and that his wonderful book "Illness Narratives" [2] describes so beautifully. I believe the difference was that he was now willing to hear and to face the reality of this patient's suffering. The first lesson about narratives in medicine is that stories are how patients communicate and experience their suffering and our first crucial step is to face those stories and the suffering they portray. The change is less a matter of skill or expertise and more a matter of intent and courage to move towards that painful place.

Narrative Medicine

Arthur Kleinman was a clear proponent of whole person care, including the divide between disease and illness and curing and healing. He saw an attention to illness narratives as a way to increase the focus on healing which was being increasingly eroded by the technological, fix-it trend of modern medicine. When I saw him speak towards the end of his career, he appeared to believe that any attempt to move medicine in the direction of caring and healing was virtually hopeless, despite his own and others' best efforts.

However, the work of Rita Charon gives me a reason to hope. Rita is the leader in "Narrative Medicine" through her publications [3], workshops, a book [4], and an educational program at Columbia University in New York. As an excellent and dynamic workshop leader and speaker, she proposes that a specifically literary focus on patients' narratives can increase empathy and affiliation with patients. She would suggest that narrative competence is an essential part of the skill set of a medical practitioner.

I have attended a number of Rita's lectures and workshops and came away stimulated and educated. We did a number of exercises including writing our own stories, reading others' stories, examining a literary text, and using literary concepts to analyze what we were writing, reading, and learning. I got a

sense of the importance of listening to stories, our own and others', and that stories were not merely a report on what happened or the meaning that we gave it but that we actually created meaning by the stories that we told. And the meaning we create is affected by the listener as well as the speaker. Therefore, healthcare workers do not merely listen to (or not listen to) their patients' stories, they cocreate the stories and their meaning by how they interact and listen. I have no doubt that this is an essential part of the healer's art that Rita Charon and people like her are helping to foster and promote.

Narrative, Power, and Therapy

Michael White and David Epston are the leaders in what has been called Narrative Therapy [5]. They are family therapists who take the narrative approach one step further. Rather than limiting themselves to listening to and honoring patients' stories, they take a more active role in changing or supporting different versions of a patient's story. Their work comes from a realization that stories are a form of power and they would like to put that power firmly in the hands of the patient [6]. They point out that we all live within stories that are created by the dominant culture. This culture could be political in the largest sense, religious, gender based, or indeed medical. And sometimes these dominant stories can be very disempowering. One medical example is when the diagnosis of a disease is treated as the patient's identity. So instead of being a person with renal failure, I become a renal failure patient, or a diabetic. White and Epston work for ways to nurture more empowering stories that lead to healing. This includes externalizing the problem [7]. The importance of the separation of the disease from the person in whole person care is informed directly by their work. They also employ other techniques to loosen the grip of disempowering stories (for instance, by searching out exceptions to the dominant theme) and to increase the force of empowering stories (for instance, by different forms of witnessing, including the use of documents for that purpose [8]). I have no doubt that as we develop further the healing aspect of whole person care, we will become more involved with our patients' stories as therapeutic tools.

Zen Stories

The three approaches to narrative I have outlined have a distinctly Western flavor. They attempt by analysis and reflection to understand stories from different perspectives. Kleinman might be said to have a primarily

anthropologic focus, Charon a literary frame, and White and Epston a focus on power relations. All these are useful and lead to specific interventions and approaches that may be very helpful. There is another approach to stories that has a completely different purpose. If the Western approaches outlined might be said to help us to think more and differently, Zen stories seem to have the objective of stopping us in our thinking tracks [9]. A typical example would be the story of the Zen master Kyogen [10]. He posed the following dilemma. A man is up a tree and hanging on to one of the branches by his teeth. He cannot reach other branches with his hands or his feet. There is another man under the tree who asks him “What is the meaning of the Bodhidharma’s coming from the West?” If he does not answer, he will not satisfy his questioner. If he answers he will fall down to his death. How would you respond? The purpose of this Zen koan is to defeat the logical brain so that the intuitive mind can work. Does this also have a role in medical care?

I told a story earlier of a surgeon who when asked by his patient if she would survive her ovarian cancer answered, “Ask me again in 2 years.” It was a logically reasonable answer with devastating effects. It might have been equally counterproductive to answer yes, she would survive, since that would be expressing a certainty he could not justify. And to have responded simply no would have clearly been unacceptable. What should he have said or done? The first step I believe would be to have stopped in his tracks before proceeding. Perhaps he should have sat down, held her hand, said he would come back later. It is impossible to say what should happen without being in that context at that moment. What will matter most in whatever follows is not the specific response he gives but the quality and depth of presence he can bring to that moment—the very qualities a Zen koan is meant to stimulate and test.

“I Like the Way You Scratch a Hog”

But perhaps Western and Eastern approaches to stories meet at the level of experience [11, p. 203]. Whatever our initial perspective, a focus on stories makes us more fully present to experience and opens the way for the intuitive mind to work. Therapist Milton Erickson tells a story from his youth [12, p. 59–61]. Erickson was selling books to support his college education and walked into a farmer’s yard in the late afternoon. The farmer said he had no interest in books. His only interest was his hogs. Erickson asked if he could nevertheless stay and talk. The farmer said sure, he was feeding his hogs. Erickson stood and told the farmer about his books. As he did so, he

unconsciously picked up a shingle and began to scratch the hogs' backs, which as a farm boy he knew they liked. The farmer stopped, invited him to dinner, and said he would buy the books saying, "Anybody who knows how to scratch a hog's back, the way hogs like it, is somebody I want to know."

What is the message of this story? How to sell books? How to manipulate others? No. But in really listening to the farmer's story about his hogs, Erickson made space for his intuition to respond in a way that his logical brain could never have worked out. I suspect that is what happened when Kleinman began to ask that young girl about her suffering. That question and his listening brought him and his patient more fully present to each other—the primary function of narrative in healing and whole person care.

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Chapter 14

Digital Media and Medicine

“The medium is the message.”

Marshall McLuhan

My colleague, Dr. Mark Smilovitch, is about to present to the first year medical class of some 180 students on the healer role as applied to cardiology. I have seen him give the talk before and it is excellent. He is always well prepared starting with slides of an EKG and a video showing the process of coronary occlusion to connect with students' scientific frame of reference. He then moves to the patients' experience putting on the screen a website of patients telling their own stories. He stresses the importance of images and the words we use putting up a slide from medical advertising showing the heart as a ticking time bomb. He ends with one of his patients who stands in front of the class and tells of her own experience with coronary artery disease.

It is a great talk, and I am looking forward to sitting back and enjoying it, except it is not going to work that way today. The projector has become disconnected from the computer screen. After some determined, desperate, and failed attempts to fix the problem, Mark decides to go ahead without slides. The result? Much better than his usual talk. The students are more engaged, I am more engaged, and although at times he seems to be struggling slightly, his message comes across very loud and clear. But how does less suddenly become more? And conversely, how did the “more” of excellent visual slides, video clips of patients, and animated cartoons of coronary occlusion become “less”? The answer is exactly analogous to the effect of digital media on medical practice. The proponents of the electronic medical record and other electronic aids to medical practice are not wrong. It is more. And in an important way, it is also less. And working out this “more” and “less” is an important and unresolved challenge for medical practice and whole person care.

White Snake

On the white snake curative side of medical practice, electronic media are by and large a positive influence. It makes sense to be able to pull up all of a patient's lab results rapidly on a computer screen or for a radiologist at a distant site to see and report on a patient's CT scan. It is helpful to have written medical reports that are typed and legible rather than scribbled in a doctor's illegible handwriting. The patients' medical records should be immediately available at whatever healthcare institutions they visit for care.

But even on the white snake side, the effects are not an unalloyed benefit. Have you ever noticed how annoying and time-consuming it can be to complete a form on the computer? It often asks for information that you consider irrelevant and seems to get in the way of what you want to ask and express. It will not allow you to leave out fields that it considers mandatory (the usual red warning sign) but often seems to miss what you consider the key element or big picture. Even when we are not actually using the computer, I believe this kind of thinking and communicating can become part of our operational procedure. And the effect can be disastrous for the white snake side of medical practice.

It turns out that Mark's patient who related her story to the class illustrated the problem very well. She noticed that when she walked up a particularly steep hill on her way to work, she developed a pressure in her chest and a burning pain that went down her left arm. The pain did not occur with less severe exercise but was reproducible walking up the same hill. She thought immediately "There is something wrong here and it is probably my heart." It was an absolutely classic story of exercise-induced angina in a woman in her 50s without cardiac risk factors.

She was worried and went to her family doctor who sent her to the hospital. She had an exercise stress test that showed a normal result. She noticed that the stress test did not really test her as climbing the hill had done but did not feel able to say anything. She was sent home with the reassurance that everything was okay. The appropriate protocol was followed, the appropriate boxes ticked, end of story.

But of course it was not the end of the story. Luckily she herself remained worried and after some period of deliberately slowing down tried herself again on the same hill, with the same result. She went back to her doctor and had further tests including an angiogram that showed a 90% occlusion of one coronary artery, which was treated by angioplasty.

But how does this initially missed diagnosis apply to electronic media? I believe it is the same phenomenon that we experience when completing electronic forms that prevent us from seeing or expressing the big picture. It is what

Kahneman might call thinking fast versus thinking slow [1] and what Senge et al. would call reactive thinking versus deep thinking [2]. Electronic media do not simply supply information; they induce in us a particular form of thinking and being that focuses our attention on particular granules of data (boxes to be ticked) and can distract us from the big picture, the underlying context that is essential to make sense of our patients' stories and findings.

Fast Thinking, Reactive Thinking, or Not Thinking

There is something to be said for my suggestion that electronic media encourages fast thinking (the use of shortcut heuristics to address complex problems [3]) and/or reactive thinking (the downloading of preset mental models [2]). In both formulations there is a rush to rapid intuitive judgment. But what I find is that a computer or electronic interface may completely shut down my intuitive thinking. I am so preoccupied with ticking boxes I may abdicate my own judgment and thinking. I merely tick the boxes and leave the rest to the computer. I wonder if something like this happened with this patient. Possible angina: tick the box of exercise stress test. Stress test normal: reassure the patient and move on to the next problem. Where was the concern that should have remained for a patient who presented with a very convincing and potentially threatening set of symptoms out of the blue? The only person who appeared to remain worried and thinking was the patient.

Black Snake

On the black snake side of the medical dichotomy, the adverse effects of electronic media are even more clear-cut. The primary task of the health-care practitioner on this side is to establish a healing relationship with the patient. And electronic media generally are more a problem than a help in this regard. If the primary ways of communicating relationships are analogue [4], then the specific digital information that the electronic medical makes available should be background rather than foreground. As a patient I want to sense that you are really listening to me, that you really care, and that your emotions and not just your thinking are fully engaged. If you seem more interested in the results on the computer screen, interrupt our conversation to answer your cell phone, or are preoccupied with a box ticking internal dialogue as I speak, I am likely to go away feeling very

disregarded as a person and unsupported in what lies ahead. This is not simply a skill in communication techniques that doctors and other health care practitioners need to learn but depends on the authentic depth of their relationship with the patient. There are different ways this can be described. In previous discussions, we have called it congruence: full presence to self, other, and context [5]. The key step in being congruent is empathy: the ability to stand, to the extent I can, in the patient's shoes while still standing on my own. And there are multiple studies showing that electronic media appear to interfere with empathy.

In her book *Reclaiming Conversation: The Power of Talk in a Digital Age*, Sherry Turkle does an excellent job of reviewing the available evidence [6]. This goes from secular trends in the empathy of college students in the US coincident with the rise of electronic media [7], to widespread detrimental changes in education with the availability of cell phones [8]. It appears that even the presence of a cell phone on the table between two people having a conversation decreases the depth of the conversation [9]. And yet, at least where I work, there is a computer in every doctor's office to which the physician will frequently refer and may record his notes in the course of the interaction with the patient. It is done I believe with a view to improving the efficiency and value of medical care.

High-Value Medical Care

There is a recent move across North America to focus on the high value of some of our investigations and treatments and do what is possible to favor those aspects of medical intervention over interventions that are of less high value [10]. Value is expressed as a simple formula of outcomes (including the outcome of patient satisfaction) divided by costs. There is a sense that in our very busy system we do a lot of things that are of marginal value, and some even downright detrimental, and we need to diminish this overuse in favor of what is really helpful. There are public campaigns aimed at both public and healthcare practitioners [11] to promote this important initiative.

Where do electronic media fit into this high-value care discussion? To answer that question, we need to answer a simple question: what is the most high-value aspect of medical care? Is it the tests that we order, the medications we prescribe, or the surgery that we do? All of those things can be valuable and even lifesaving, but there is an aspect of medical care that accompanies or precedes all of these interventions, drives decisions, determines outcomes and patient satisfaction, and increases the value of care for

both patients and healthcare workers. That central feature is the quality of the relationship between the patient and the healthcare worker [12]. That relationship is not only important on the healing side of the medical dichotomy but also important on the curative side. It will determine whether tests are ordered and medications prescribed out of anxiety, distraction, or a real reflection on what is likely going on and what will most likely be helpful; it will allow the patient to question and play a full role in choosing how to proceed, and it will of itself improve patient satisfaction and promote healing. It is in the context of this central relationship and probably highest-value aspect of healthcare practice that we must make decisions about and evaluate the use of electronic media in healthcare.

The Digital Doctor

The depth and scope of the effect of electronic communication on medical practice is beautifully explored in Robert Wachter's book *The Digital Doctor: Hope, Hype, and Harm at the Dawn of Medicine's Computer Age* [13]. Speaking from personal experience and a profound knowledge of the recent growth of the digital revolution in medicine, Dr. Wachter sees huge potential benefits and surprising problems that directly flow from those benefits.

Perhaps the most clear-cut benefit of electronic media is the ability to make huge amounts of information available at any location that has a computer connected to the network. It turns out that this benefit was realized earliest in radiology with resulting paperless and filmless departments [14]. No one would return to the old system, and yet there has been a significant loss—the personal and academic connection between radiologists and the physicians directly caring for the patients. When Dr. Wachter was being trained, the only place to see a patient's films was in the X-ray department. Teams met there on a daily basis with the concerned radiologists to review the films and learn from each other. According to Dr. Wachter, this was one of the richest opportunities for learning during his training [14]. Now, as he reports, radiologists sit in front of computer screens and dictate reports—no interaction, discussion, or teaching [14].

What is the essential loss here? I would say it is of relationship between colleagues. And it is mirrored in all of the other relationships in the healthcare system. We said earlier that the only place to see the patients' films was radiology. It was also the place to find the radiologist—not a disembodied presence expressed in dictated reports but a real living, breathing, thinking, and interacting human being. As electronic media have facilitated other disembodied

examples of communication—between physicians and other healthcare workers, between healthcare workers and administration and/or payers, and most importantly between healthcare workers and patients—we have lost something vital. We are more like separate cogs in a huge machine than human beings with important relationships that enrich and sustain our lives [15].

This is important in all phases of medical and healthcare practice, but nowhere does it have more impact than on the most important relationship of all—the doctor-patient relationship. As more and more information is available without seeing the patient, doctors spend less time with their patients and more on computers and even when they are with their patients, they are often looking up results or typing out a report of the interaction in the patient's presence. As Abraham Verghese has expressed it, often the iPatient receives more attention than the living breathing patient [16]. But why does electronic data get in the way of our interaction with a living human being?

I believe that there are a number of reasons. First, the sheer volume of available digital information is so overwhelming it takes all of our cognitive capacity to deal with it. There is simply very little left over for anything else [17]. Second, we are prone to distraction [18]. Third, and perhaps most importantly, when under stress we tend to leave out essential parts of an interaction. This is the phenomenon of Virginia Satir's communication stances [19]. And the stance that electronic media tend to induce is the super reasonable stance in which we leave ourselves as a person and the other person as a person out of the picture. We focus purely on solving problems. It was perhaps prophetic that Satir's other word for this stance that predated the advent of the electronic medical record by many decades was the computer stance [20]. I believe that this use of electronic media is the explanation for the decline in empathy as reported by Sherry Turkle. It is a problem in society at large but clearly a profound threat to the doctor-patient relationship and to the black snake side of medical practice.

The Solution

What will be an effective response to the problems raised by electronic media to healthcare practice? The first I believe would be to acknowledge the depth and extent of the threat. This is not Luddism or an attempt to hold back change but to realize the need to put measures in place that protect what is vital and essential to healthcare practice. Dr. Wachter hopes that as the technology improves, the problems will resolve, and we will all be much better off [21]. I am less optimistic. Is it not likely that whatever benefits accrue with better machines they will also come with powerful and unforeseen consequences that we will need to have mechanisms to handle?

I believe that the answer lies in a renewed commitment and a specific focus on one aspect of medical practice. I believe that we need to focus on the central aspect of being a medical professional—the ability to relate in an effective and healing way to a sick patient [22]. Everything else is secondary and must be subservient to that overriding goal. Rather than be swept along by the digital revolution, we need to make choices both individually and as a group that honor our primary commitment—to individual patients that come to us for help. I believe that a commitment to whole person care with the skills and priorities it encompasses is the way to achieve the required balance. Not as a way to slow down the electronic revolution, but to ensure that it synergizes with medical care and caring to provide the greatest benefit to our patients. And in that endeavor I believe that Marshall McLuhan’s quote at the beginning of this chapter is highly relevant. Probably the most powerful factor in establishing and developing a helpful and healing relationship with patients is not the information we obtain or impart but the primary medium we use to conduct that relationship. I believe that primary medium has to be embodied, personal, face-to-face human conversation and interaction—analogue communication. It is not that other modes of communication cannot be helpful, but they are secondary and will only detract from the interaction if they are given a too prominent place. Perhaps it is the great power of analogue communication that Dr. Smilovitch inadvertently discovered in his interaction with the medical school class.

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Chapter 15

Prevention and the Whole Person

“Many things are true at a low level of being and become absurd at a higher level, and of course vice versa.”

E. F. Schumacher

Prevention of disease always seems like a good idea.¹ Who could argue against taking measures to prevent a heart attack or detecting cancer early (at a stage when it can be removed or effectively treated)? These disease-focused measures aimed at prevention make such good common sense that it is hard to argue against them and we would not do so because they really can work. And yet there are problems with these approaches that often elude common sense. We believe that these limitations need to be appreciated and the preventative measures aimed at disease need to be bolstered and adjusted by complementary measures based on the whole body and the whole person.

Primary Prevention

What are the limitations of disease-based prevention? First, the limitation of *primary* prevention [1] aimed at stopping disease before it occurs (as in taking cholesterol-lowering drugs to prevent a heart attack) is that we need to target appropriately those whose risk of disease is sufficiently high to justify the side effects and costs of the intervention or medication. This is fairly straightforward if we limit ourselves to those at the highest risk levels in whom the individual benefit will be substantial. However, if we restrict our interventions in this way, we will miss most of the disease occurring in the population which will continue to come from the much larger numbers of

¹ Reprinted from Hutchinson TA. (Ed.). *Whole Person Care. A New Paradigm for the 21st Century.* New York: Springer Science + Business Media, LLC; 2011.

people whose individual risk is not high—a phenomenon known as the prevention paradox [2]. It is not clear if we can prevent the majority of diseases by primary means because as we begin to extend our preventative measures to those at lower risk, the overall costs (both financial costs and the costs of side effects) will increase, and the benefits to individuals will decrease. However, there are other factors at play. The studies to establish the cost-benefit ratio for individual patients will need to become larger and more complex. Large pharmaceutical companies, unlike individual patients, or governments and other third parties, who may pay for the medications, necessarily benefit the wider the preventative treatment is disseminated. The high costs of the necessary studies are usually borne by these companies because only they can afford to fund them. What trials are done and how the results are publicized to affect prescribing may be more determined by concerns for profit rather than what is best for individual patients or the public health [3]. We need to be cognizant of these influences unrelated to public or individual health when we make decisions about primary prevention.

Secondary Prevention

The limitation of *secondary* prevention [1] aimed at early detection and treatment of disease is the tendency of detection methods to overrepresent mild and even insignificant disease. Why does this happen? For illustrative purposes, take two cases with the same kind of cancer. Case 1 is a patient with very aggressive and rapidly progressing cancer. The time from first appearance of detectable cancer to the onset of symptoms necessitating a doctor's visit is 3 months. Case 2 is a patient with the same kind of cancer but not so aggressive or rapidly growing. The time from first appearance of detectable cancer to symptoms severe enough to prompt a doctor's visit is 3 years. What kind of cancer do you believe will most likely be detected by screening? The answer is the second kind, and the difference of their representation in those detected by screening is a factor of 12! It is difficult to test often enough to detect the really severe cases, and more sensitive diagnostic methods do not help, leading mainly to the detection of more and more of the mild cases [4] with slowly progressive disease.

Clinical epidemiologists have long been aware of this problem [1] and the resultant effect that screening always appears to look good because the cases detected tend to be mild from the outset. For this reason, researchers insist on randomized trials to evaluate screening methods. And the results are sometimes very surprising. In one famous study from the Mayo Clinic [5], smokers were randomized to be screened by four monthly chest X-rays and sputum tests compared to a similar group who were randomized to regular

care. As expected, the group randomized to four-monthly X-rays and sputum tests had more cancers detected, more surgery to remove them, and a better survival in those with cancer detected. But here is the surprising result. The overall mortality and the mortality due to lung cancer were identical in the two groups. It appears that the regular testing swelled the number of those labeled as having lung cancer but did not change the number of patients dying from lung cancer in the screened group. And the results remained the same after 20 further years of follow-up [6].

Does this mean that screening is useless? No, but we need good randomized studies and perhaps need to look again at our simple model of disease. The model of disease upon which most prevention is based is that disease (cancer or other) starts with small changes, progresses to a point where it is detectable but not symptomatic, and continues to progress until it produces symptoms, dysfunction, and possibly death. But, surprisingly, there is evidence that a significant proportion of cancers detected by screening are not life-threatening [7] or progressive [8], and some detected cancers appear to regress spontaneously [9]. The varied spectrum of biologic behavior in cancer and other diseases, combined with the costs and side effects of testing and follow-up interventions, explains why disease-based prevention based on early detection may be useful for some diseases but not for all diseases in all patients. We need to target our detection and intervention more precisely to diseases and people at risk for those diseases who stand to benefit from screening. This is an ongoing process that has resulted in recommendations, for instance, that routine mammography screening is worthwhile in women between 50 and 74 years of age but not in younger women or older women [10]. There is an analogous need for very precise targeting in primary prevention where, for instance, how seriously we should take and treat a high cholesterol value depends not just on the level of the abnormality but on the balance of other risk factors for heart disease in the person being evaluated [11]. The complexity of our bodies and different disease processes that makes disease-aimed prevention not always the clear answer for most people has another implication—we may need a complementary method that fills the gaps in our preventative armamentarium.

Whole Body Prevention

We suggest that an approach based on the whole body and the whole person is what is needed. Whole body prevention is doing things that have multiple beneficial effects on the whole complex organism that is our body. A good example is regular exercise which appears to help

prevent obesity; control lipid abnormalities, diabetes, and blood pressure; improve psychological functioning and prevent depression; decrease the risk of major diseases such as heart disease and some cancers; slow the development of osteoporosis; and keep people more functional and mobile for longer. A short list of things we can do, which appear to be good for the whole body, are: get regular exercise [12], eat a healthy diet (good food, not supplements) [13], sleep enough [14], manage stress [15] (e.g., mindfulness [16] and other approaches), and avoid injurious habits (e.g., smoking). You will notice that every one of these measures not only has multiple and complex beneficial effects but also tends to improve quality of life and well-being, which might be an equally good reason for doing them. We tend to think of prevention as aimed primarily at future survival but should not preventing or reversing a decrease in quality of life also be important? And in these whole body preventative measures, we appear to be able to have it both ways. What then is whole person prevention and does it have the same attractive properties?

Whole Person Prevention

Whole person prevention is aimed at preventing a loss of meaning [17] or increasing the depth of meaning and connection [18, 19] in our lives. So it might be said that disease-based prevention is aimed at survival, whole body prevention is directed towards survival and quality of life, and whole person prevention is concerned with meaning and the effect that it has on our survival and quality of life at a deeper level. And interestingly the measures we might take based on these three approaches do not always seem to agree. Consider the following story about Viktor Frankl from the film “The Choice is Yours” [20].

Frankl is living in Vienna, the Nazis have invaded Austria, and the writing is on the wall for Jewish citizens like Frankl and his family. He has applied for a visa to go to the United States which arrives, making everyone including his parents happy. He at least will be saved. But this will leave his parents in Vienna at the mercy of the Nazis. He does not know what to do and asks the world for a sign. That night he notices that his father has brought home a piece of marble from a destroyed synagogue. It is a piece of one of the Ten Commandments. His father asks him “And do you know which commandment this marble is from?” The answer is “Honor father and mother and stay in the land.” Frankl stays and ends up surviving Auschwitz and writing “Man’s search for meaning” within months of his release. His parents and wife die in the camps.

Our natural first thought is that the surest way for Frankl to have preserved his life was to take the visa to the United States. But that might have meant going against his deepest values. What does “his life” mean in this context? Is it just his body or is there a larger meaning to this term that includes the whole person and the values, meaning, and relationships that are important to that person? Did Frankl take the only option open to him to preserve his life in this larger sense while risking his body? In our desire to prevent bad outcomes, do we need to take our values into consideration?

There is a clear relationship here to the two sides of the Hippocratic/Asklepian dichotomy. In the Hippocratic mode, we should do everything to preserve the body and control the future. In the Asklepian mode, we may need to focus more on preserving our values, which includes what we enjoy in life, and lessen our grip on the future survival of the body. One way of getting at this is to ask ourselves why we may want to live a long time. The answers would differ for each person, but for myself, I might say, for instance, that I want to continue to enjoy life, to see and nurture my grandchildren, and to leave a legacy. The next question is whether I am living my life in line with those goals right now. Am I enjoying life fully right now? Am I doing everything I can to nurture my future grandchildren? Am I actively working on my legacy? I find that this is a strangely and surprisingly healing process. The truth is that none of us knows what is in store for us. The best preventative measures may not foresee or avoid what is actually on the cards. But we can do something about the present. For instance, when I ask myself the three questions that I posed earlier, the answers are surprising. Am I enjoying life to the full right now? Well not really because I am waiting for something to happen (to retire? to get older? for something else but for what?). Am I doing everything I can to nurture my future grandchildren? Not really because although I know that it is very important to me, I hardly ever think about it. Am I working on my legacy? Indirectly but mostly I am not aware of it one way or the other. It is not that achieving those goals is important for its own sake, but confronting those questions has a profound effect on my being in the current moment. I have a sense of calm energy when I ask myself those questions that I believe may be the best tool we have to optimize our current health and well-being, to prepare ourselves for whatever the future may bring, and possibly even to preserve our lives.

Does this mean that we should stop exercising? No, but perhaps we should take it on with more flexibility and in ways that fit the rest of our lives and that we enjoy more for their own sake. It might mean joining a tennis club rather than taking regular solitary visits to the gym. Perhaps we should do it less out of duty or fear and more out of enthusiasm or love for the exercise activity. Perhaps our better diet becomes less a matter of restriction and more a focus on mindful enjoyment of foods that we thoroughly savor. One advan-

tage here is that we are much more likely to continue an activity that we really enjoy. But at a deeper level, I believe that enjoyment of the present moment is our best preparation for the future. Why? Because the future is inherently uncertain, things will happen that we do not expect, and our challenge will be to get the most out of whatever happens. Our best prevention may be to learn how to enjoy the present moment and by extension all future present moments. Focusing primarily on trying to avoid “bad” things happening is ultimately doomed to failure with the added complication that what we thought would be “bad” events can turn into “good” events—turning points in our lives that open us to a deeper and more meaningful experience of being alive, as often reported by patients with serious illness [21].

Conclusions

Where does this leave us? We would conclude the following:

1. Disease-based prevention methods should be continued but only in those situations where there is clear evidence based on randomized trials that they work to prevent significant disease in the persons targeted.
2. Whole body-based prevention methods are almost always a good idea because they work on multiple systems at the same time and generally have immediate effects on quality of life and well-being.
3. Taking whole person concerns into account may significantly modify how 1 and 2 are best implemented in different people.

Lastly, since the extent to which people are in touch with their deep values may determine their quality of life now and in the future, this should be an overriding concern in prevention, especially given the inevitable uncertainties in people’s very complex and changeable lives. Because patients are whole persons in which all the parts are connected, we cannot limit ourselves to the Hippocratic side of the medical dichotomy in prevention any more than in treatment. We are just beginning to scratch the surface of what good preventative measures mean in whole person care.

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Chapter 16

Whole Person Evidence

“Contemporary nihilism no longer brandishes the word nothingness; today nihilism is camouflaged as nothing-but-ness. Human phenomena are thus turned into epiphenomena.”

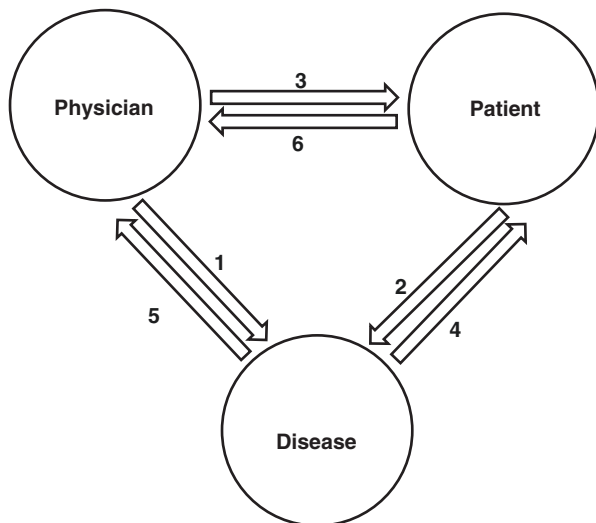
Dr. Viktor Frankl

When at the start of this book I reported that my wife and I felt better after we had smoked cigars and drank sherry in her room at the hospital, does that constitute evidence? And what about Balfour Mount’s report on his patient CD who despite his physical deterioration and the progression of his testicular cancer said that this had been the best year of his life [1]? Certainly these anecdotal reports would not appear to fit what David Sackett would call best research evidence although they could possibly be incorporated into evidence-based medicine (EBM) under the headings of clinical expertise or patient values [2]. But perhaps there are different kinds of evidence that are relevant to different aspects of the medical mandate.

Different Kinds of Effects and Evidence

If we examine the relationships between patient, physician, and disease shown in Fig. 16.1, we will see that there are six kinds of effects that we could study because each of the three relationships shown is bidirectional. It turns out that EBM focuses primarily on one of these—the effect of the physician’s interventions on the disease. And this leaves five potential effects relatively unstudied: the effect of the patient’s wellness on the disease, the effect of the physician’s presence on the patient, the effect of the disease on the patient, and finally the two effects that point directly back at the physician—the effect that the disease in the patient has on the physician, and the effect that the patient as a person has on the physician. We will examine each of these in turn.

Fig. 16.1 Different kinds of effects and evidence. (1) Physician on disease, (2) Patient on disease, (3) Physician on patient, (4) Disease on patient, (5) Disease on physician, (6) Patient on physician



The Effect of the Physician's Interventions on the Disease

This is the primary concern of EBM. We wish to bring as much hard evidence to bear on whether what we are doing actually works. This is an essential first step that allows us to differentiate real from imagined or hoped-for results. We call on this evidence when we wish to confirm the effects of a new chemotherapeutic agent or a medication to lower blood pressure or cholesterol. In EBM we generally grade the evidence as to its scientific validity with the top level for assessing therapeutic efficacy being the randomized, controlled clinical trial [3]. And sometimes such trials produce surprising effects, which are very helpful and clarifying. To give an example from my own experience, I was working at the National Institutes of Health with a group who had uncontrolled evidence that respiratory muscle rest had markedly beneficial effects on patients with chronic obstructive pulmonary disease. When doctors took patients with this disease and rested their respiratory muscles overnight by putting them on a respirator, their PCO_2 levels and exercise tolerance improved dramatically. We proposed a randomized clinical trial where patients would be randomly assigned to be put on a nighttime respirator or not. It was pointed out to us that patients would know whether they were in the active or placebo arm of the trial and this knowledge itself might affect the results. We placed everyone on a respirator that looked and sounded exactly the same except that in the placebo arm the settings of the respirator were such that they did not take over the

work of breathing [4]. And the results? No effect of respiratory muscle rest on patients with COPD [5]. Similar trials have disproved the efficacy of many treatments that appeared to be effective in uncontrolled studies and, of course, proved the effect of many other treatments. The primary focus here is to remove or control for the placebo effect so that the direct effect of the intervention on the patient's body can be determined.

Mind-Body Medicine: The Patient's Effect on the Disease

There is extensive research on the effect the patient has on the disease. This is well reviewed in a book by Anne Harrington titled *The Cure Within: A History of Mind-Body Medicine* [6]. She describes the physicalist framework of modern medicine that ascribes the cause and cure of all disease to physical factors—tissue, blood, and biochemistry. She then contrasts this with the traditional framework that ascribes disease and cure to religious, moral, and social stories such as personal sin, evil in a community, a test of faith, and other explanations that have largely been discredited [6]. She points out that there is a third way that neither restricts itself to the narrow physical explanations of biomedicine nor accepts the traditional beliefs and stories but sees disease and cure as being affected by the mind as well as the body [7]. So what one thinks and feels and what kind of person one is can have real effects on disease. She gives one particularly dramatic example of a Mr. Wright who suffered from a lymphosarcoma [8]. Mr. Wright responded dramatically both subjectively and objectively as measured by the size of his tumors to a drug called Krebiozen. When reports questioning the efficacy of Krebiozen appeared in the newspapers, his disease relapsed. But here is the really interesting part. When he was convinced by his physician that he should not believe the newspapers and that he would receive a dose of extrapotent Krebiozen, he became enthusiastic about the drug again. He received an injection of distilled water that he believed to be Krebiozen with effects on subjective symptoms and tumor size that were even more dramatic than his initial response. The story and many others in the book leave me in little doubt of the efficacy of mind-body medicine.

What are we to do with this information? First, I believe that we should take mind-body medicine seriously, which means that how we relate to patients and how they relate to their disease probably can affect the course of disease and biologic outcomes. This does not mean that we need to deceive

people like Mr. Wright but that we need to focus on and study how our relationship with patients and their relationship to their disease can affect their outcomes. Exactly how this could be studied would require further thinking similar to the thinking and development that has gone into EBM in the past two decades. This might involve many changes, but one possible development would be the routine inclusion of an untreated non-placebo arm in clinical trials. For instance, if in our study of respiratory muscle rest we had included such an arm (patients sent home without a respirator), we might have found that those sent home with a respirator, whether or not with respiratory muscle rest, did much better than the third group without a respirator. We would then need to explore, perhaps using qualitative methods, how the respirator, apart from its effect on resting muscles, could have this effect—hope, suggestion, a sense of being cared for, and other effects—and how these effects could be produced without the machinery of the respirator. And it might be that these effects would be worth focusing on and making part of our practice even if they had no effect on biologic outcomes, which brings us to the third strand of evidence relevant to whole person care.

The Effect of the Doctor's Presence on the Patient

There are various levels at which the doctor's presence might affect the patient. The first would be the immediate comforting effect of having another person present when we are suffering. Some years ago, my daughter had an operation on her thyroid gland, and when she awoke, the surgeon was sitting by her bedside holding her hand and explaining what had happened during the surgery. She still talks about that doctor. And perhaps one level of measurement of a doctor's effect on the patient is the happiness or satisfaction with care given. Many healthcare institutions appropriately use standardized measures of satisfaction with care as indications of whether their healthcare workers are doing a good job of relating to their patients [9].

These straightforward measures of patient satisfaction as evidence that the doctor-patient relationship is working are good as far as they go but leave some important unanswered questions. They might be considered analogous to using ratings of teachers by students as evidence that teaching is working. In teaching, we would also want to know that students were meeting the objectives set for the teaching. Is there an analogous set of objectives that we hope will be achieved by the doctor-patient relationship? In other words, is it just about being nice or is there important work being achieved in these relationships?

We would say that the primary work of the doctor-patient or healthcare worker-patient relationship is the promotion of healing [10]. Healing is growth in response to injury or illness [11]. What we are interested in here is growth of the person, not necessarily improvement of the disease, desirable as that may be. How can we measure growth in response to injury? This is undoubtedly a difficult challenge and one that I am not aware has been formally addressed in the medical literature. The measurement would probably have to be in narrative form since each person's growth would naturally be very different. Narratives of the experience of illness and healing have been published for some medical diseases [12] and by organizations such as Alcoholics Anonymous [13]. These narratives can provide powerful accounts of healing responses to disease, but it would take a further level of qualitative analysis to assess the healthcare workers' contribution to, or possibly obstruction of, healing. We would further like to know, assuming there was such an effect, what it was in the healthcare workers' relationship that was most important in producing the effect. Without such information, we are teaching healthcare workers aspects of communication and relationship that we believe are important on a common sense basis but without evidence to back up our assumptions [14]. We are aware of the research in the psychological literature that empathy, warmth, and the therapeutic relationship are more important in determining the outcome of therapy than the specific therapeutic approach used [15]. We currently teach communication- and relationship-centered care primarily as a set of learnable skills [14]. It might be that it is the underlying attitude and intention of the healthcare worker that is the key ingredient, whether or not they have learned specific skills.

The Effects of the Disease on the Patient

The effect of disease on patients is presumably the main reason for medical intervention in the first place, and we do have research on the quality of life of patients with different diseases. Patients' quality of life is affected less by serious disease than one would expect or even than the patients themselves might have expected when they were well. This appears to be due to a phenomenon called response shift in which how patients measure their quality of life may change when they become ill [16]. This results in surprising and sometimes counterintuitive findings, such as the high subjective quality of life of patients with disability [17]. One possible approach to this challenge is to stop measuring global subjective quality of life and to focus on specific measurable effects of disease that would be expected to affect a person's

sense of well-being [18]. A more productive approach might be to look with more depth into the complex relationship between disease and quality of life in order to identify the details and timing of this relationship. To take a concrete example, it would be important to know what factors determine the subjective quality of life of patients starting dialysis treatment for end-stage renal disease, what the changes are over time, and how the effects seen can be mitigated. If our primary purpose in whole person care is to relieve suffering caused by disease, then this kind of information would provide an important evidence base for our practice.

The Effect of the Disease and the Patient on the Physician

To a degree how the physician is affected by the disease and by the patient has been studied, primarily for the negative effects on the physician. The direct effect of the disease on the physician is part of the larger body of information on the effects of the medical environment on physicians which can result in burnout [19]. The effect of the suffering of patients on physicians has been studied under the rubric of compassion fatigue [19]. These are important areas of research but need to be balanced by the study of the positive effects of these phenomena. As Michael Kearney has pointed out, relating to suffering in sick patients can result in healing for both patients *and* physicians—an improved rather than a decreased quality of life [20]. I do not know of studies of the positive effects on physicians of treating disease and working in a medical environment, although there are many potential benefits—satisfaction from successful treatment or a technically well-performed procedure, increased self-esteem, positive feedback from patients and colleagues. We need to study these effects to see their determinants, how they differ in different subspecialties and structures of practice, and how they change in different phases of a medical career. In general, we need research on the positive effects of medical practice on physicians in order to balance what we know about the negative effects. Studying effects on physicians, both positive and negative, complements studies of patients and is part of a larger whole, the study of medical culture.

The Culture of Clinical Practice

The approaches described above need to be complemented by a more holistic approach that studies how the culture of medicine functions because it is the culture of medicine in which doctors, nurses, other healthcare workers,

and most importantly patients live and function. In a very reductionist milieu, it is very easy for new approaches or technologies to be introduced because they make sense as isolated improvements. However, they might possibly miss detrimental effects on the culture of medical practice, which raises another issue. If medical culture is a living entity, it has a present and a future, but it also has a past which informs and supports what is happening on a day-to-day basis. This is something that we understand very well when we speak of the cultures of nations and ethnic groups because we realize very clearly the importance of retaining a link with the past [21]. In medicine, retaining the same kind of link is almost certainly important, and yet it is relatively easy to dismiss this issue as irrelevant or even destructive. For instance, we may look back at the past as a period in which medicine was physician focused and inconsiderate of patients' needs, a regrettable past from which we have now thankfully recovered. But when I read Bliss' biography of William Osler [22] who practiced more than 100 years ago, I learn about a knowledgeable and consummate physician who was very much attuned to his patients as people. Is there a wisdom about medical practice represented by practitioners such as William Osler that is relevant and important for practice in the twenty-first century? I believe that there is and that to ignore such wisdom would be equivalent to a nation or ethnic group cutting its ties with its founding heroes—a radical move that would herald severe cultural disruption, loss of identity, and suffering. We need to study the culture of medicine both past and present so that we can bring into the future the best of what we have learned combined effectively with new approaches and new technologies. This needs to be allied with a more comprehensive system of assessment that examines all six effects that are relevant for treating everyone in the healthcare system—patients and healthcare workers—as whole persons, because the wellness of every participant in the healthcare system plays an important role in our ability to deliver whole person care.

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Chapter 17

The Organization of Healthcare

“People really are our most important resource, and people who don’t realize that and choose not to live that way, are paying a price for that in many of our companies, many of our organizations.”

Chesley Sullenberger, Airline Captain

Does whole person care and the powerful dichotomy between curing and healing have implications for how healthcare is organized? I believe that it does and that the two sides of the dichotomy have equally important contributions to make.

Curing and Hierarchy

If we take a curative approach to organization, everything is subordinate to achieving a specific result, whether it is the outcome of cardiac surgery or the survival of patients with kidney failure. Each person in the organization will be measured by their contribution to the objective(s) of the organization. We will need a clear hierarchical structure that defines who reports to whom. When something does not work, we will look for a cause, either a person or an action or inaction by someone in the organization, so that we can correct the problem. Overall we will be looking for control, and a good manager will be someone who can exert effective control so that the objectives of the organization can be achieved.

What I have just described is Virginia Satir’s hierarchical model [1]. It is I believe the usual modus operandi of most medical organizations. It seems like a good and effective model for achieving specific results. However, as in caring for patients, if that is all the organization does, it will run into very serious problems. As Satir points out, adopting this hierarchical model as the sole approach to organization affects individual people, their relationships, the way we understand the world, and our attitude to change [1]. Let us look at each of these in turn.

Individual Value

Under a hierarchical model, my value as a person is determined by the perceived importance of the job that I do. Thus, a doctor will be perceived as more important than a laboratory technician and so on up and down the line. If my job is considered of lesser importance, this perceived lack of importance is transferred to me as a person. What is this likely to do to my valuing of myself and to my motivation? Inevitably both are likely to decrease. Looking at the factors that are shown to lead to burnout [2], I suspect that much of the increase in burnout in recent decades [3] may be caused by the increasingly hierarchical approach to the valuing of people within healthcare organizations.

Relationships

In a strictly hierarchical organization, relationships are one up, one down, and information and direction flows from the top. My experience from a physician's perspective in a large healthcare organization is that this top-down management leaves the people who are working with patients feeling frustrated, not listened to, and hampered rather than helped in their work. In many organizations, management has become increasingly distant from clinical care. By this is meant not simply psychological distance but actual physical distance—managers are in a building in another area of town some miles away from clinical care areas and are rarely, if ever, seen in the hospital. As appropriate for a hierarchical top-down model, communication with managers almost exclusively consists of directives or memoranda transmitted by digital means from managers to staff. There is not much space for back and forth conversation or the communication of body language because this is not a mutual relationship. I was at a meeting recently where the clinicians in an area expressed an urgent need for a second station for bronchoscopy because of the increasing patient load. The response of the representative from management was to say that this request would be evaluated according to how it fitted with “corporate objectives.”

Causation

A feature of the hierarchical model is that it understands the world in a linear way. So A causes B causes C and so on. This causative simplification of life works relatively well in public health and epidemiology. It is important to find out that smoking causes lung cancer because then we can hope to

prevent lung cancer by getting people to stop smoking. But even here it is a simplification as expressed by the fact that if you add up the proportion of any disease “caused” by different agents (smoking, diet, genetics, and other factors), the result is more than 100% and theoretically is infinitely large because in reality it takes many overlapping factors to cause a disease [4, p. 13]. What happens when we apply this simplification to management? Instead of being concerned about the multiple factors in the culture of an organization that may have led to a bad result—overwork, poor communication, inadequate resources, unsupportive relationships—the linear approach looks for one factor and often one person to blame for the result. So if a patient expresses dissatisfaction with the care that he/she received, it is likely that one person will be identified as the person responsible, regardless of how many other factors led to this act of care. The result tends to be a culture of blame and defensiveness that may further erode the culture of care.

Change

A final feature of the hierarchical model is that it tends to be very resistant to organic change. The organization has a specific view of its mandate which it seeks to implement while tending to obliterate unique and idiosyncratic opportunities that may be harbingers of real change. For instance, I may have a receptionist who is particularly good at relating to patients and may be a key element in the care my group delivers. The organization may decide that this activity can be made more efficient by having a central booking office that deals with appointments for all physicians and groups within the institution. I have lost an important factor in my relationship with my patients and perhaps part of the development of better care within the institution. A palliative care ward within a hospital may be frustrated in the care it delivers because it must abide by a nursing patient ratio that is uniform across the institution. The key to real organic growth and change is openness to new developments that can arise anywhere in an organization, and strict hierarchy tends to dampen and flatten out those opportunities. We will look at a complementary organizational framework that capitalizes on opportunities for growth.

Healing and Growth

Just as curing corresponds to Satir’s hierarchical model, healing is another way of describing her growth model. Let us look at what effects the growth model might produce in an organization.

A Fantasy

Yesterday I went into a workplace that had completely changed. As I walked through the underground station down the corridor towards the hospital, I noticed a few of my colleagues coming in the opposite direction. They seemed to be smiling and friendly which surprised me. I wondered for a moment if the Montreal Canadiens hockey team had won a game, but it was the wrong season, and to have a real impact, they would have to have won the Stanley Cup. And then I heard the music. It got louder as I came to the end of the corridor, and I decided to go up the stairs and approach the hospital overground rather than through the underground parking since the music appeared to be coming from the open area in front of the hospital. There was a musical group collected within an open structured dome in front of the hospital, and they were playing Vivaldi's "The Four Seasons." This was the kind of phenomenon I had witnessed at the Mayo Clinic with classical music being played on grand pianos in the spacious atria of the hospitals. I realized how surprised I was to see it here but perhaps I should not have been surprised. This was after all the home of William Osler [5].

As I walked to my office, I wondered if someone had put something in the drinking water. People's usual demeanor of reserve and even fear seemed to have changed overnight to openness and friendliness. When I attended a Department of Medicine staff meeting, everyone appeared enthusiastic, interested, and open to exploring new possibilities. It seemed for a moment that everything was possible in the onward development of our desire to provide better care for patients. No one dismissed other people's ideas. Not that everyone agreed but the primary motivation appeared to be understanding each other better so that we would come up with helpful suggestions to move forward. The particular item on the agenda that day was how we should respond to a move on the part of the Ministry for Health to transfer the care of some groups of patients with chronic diseases such as diabetes and hypertension to an outside clinic that would partner with our institution. Instead of a defensive or fearful posture, we allowed our creative juices to flow and came up with four or five new suggestions that had the potential to incorporate the suggested changes in a way that would benefit our patients and our institution. I left the meeting energized and hopeful about the future.

What happened on this fantastic day? Had someone put something in the water? Yes in a way but it was not in the water but in people's minds. It is a fantasy but it captures some of what might be possible if we adopted Virginia Satir's growth model [1].

A Valuable Person

Under the growth model, every person has equal intrinsic value that is unaffected by their position, expertise, or accomplishments. Imagine if that really was the case and what that would do to individual self-esteem that would no longer be threatened by a mistake or a failure. Suppose we really believed that our value was guaranteed and we were free to give our best to the world without fear. It is something that palliative care attempts to give to patients who are dying. As Cicely Saunders put it, “You matter because you are you” [6]. Do we have to wait till we are dying to receive this gift?

A Mutual Relationship

The second aspect of the growth model builds on the first. If I am a person of equal intrinsic value to everyone else in the organization, then my relationships have to be based on equal mutual respect. This means that blind following of orders would end, and people at all levels in the organization would be listened to for their particular insights coming from their unique perspective. This would enrich the information and insights on which decisions were based. I understand that the airline industry has already adopted this aspect of the model when issues of safety are concerned [7]. But the benefits would likely go beyond safety to include greater creativity within the organization and resultant positive growth and development.

No Single Cause

Suppose that we gave up the idea of a single cause for problems and realized that in any event there are multiple interacting causes. So instead of searching for the cause and likely the person responsible and to blame, we would open our minds to the many factors involved. Would this inhibit us from acting? Not in the least. In fact we would see that there are almost always multiple areas of potential action that could solve our problem. We would be looking for creative ways to choose simple interventions or combinations of interventions that would be most likely to be successful and at the least cost, both financially and in terms of human resources. So, for instance, suppose a nurse makes repeated mistakes that endanger the lives

of patients. One response might be to identify the nurse as the problem and take steps to force a change in his/her behavior or, if that is not possible, remove the nurse from the organization. An alternative approach might be to look more closely at the context in which the mistakes took place and come up with alternate causes and interventions that might be effective. We might or might not include punitive or corrective measures aimed at the apparent author of the mistakes. Our approach, for instance, might focus on correcting perceived problems such as distractions in the work environment, workload, and availability of other support staff to help with the process.

Openness to Growth and Change

Although it might be thought that plans and clear objectives are the way to promote growth and change, they have the limitation that the change that is allowed is predetermined by the vision of the planners at the outset of the project. Most of us have had the experience that the real growth and transformation in a project occurs unexpectedly and in ways that we had not foreseen at the outset. And in the growth model, we need to be open to these unexpected opportunities that arise spontaneously in all real-life situations. In science this is called serendipity as, for instance, when Fleming discovered penicillin while he was studying cultures of bacteria [8] and Darwin discovered evolution while on the voyage of the *Beagle* [9]. Neither could have planned their discovery in advance for to do so would have meant having access to information and ideas that only became available as the project developed. We need the same humility and openness to learning new things in management and organization so that we foster real growth and transformation that arises out of the organization rather than being blunted and restricted by our limited objectives and plans.

Hierarchy and Growth

Am I seriously suggesting that we should make a complete shift from a hierarchical to a growth model? No, because we do need the characteristics of the hierarchical model to create clear lines of responsibility, to simplify the solution of some problems, and to provide a mechanism for planning the direction of change that we wish to see. At the same time, this model needs to be complemented by an openness to growth. We need both hierarchy and growth models simultaneously to get the best out of ourselves and our

organizations. There are different kinds of issues and challenges that an organization must face. Some require a heavier emphasis on hierarchy while others need to emphasize growth.

Simple, Complicated, and Complex Problems

As will be obvious, healthcare is replete with combinations of simple, complicated, and complex problems [10]. Our earlier distinction between curing and healing fits well here. Curing tends to be simple (prescription for an infection) or complicated (cardiac surgery) while healing is almost always complex (relationship between two human beings). The same is true for Satir's hierarchical and growth models. The hierarchical model attempts to simplify life or at most allows for a complicated structure of layered responsibilities, whereas the growth model is geared to the complexity of human interactions. The CEO of an organization needs a plan, a set of objectives, and a clear line of command to carry out the plan. At the same time, he/she needs to promote a culture that can get the best out of people working at all levels in the organization so that they can be responsive to the unforeseen technical and human challenges that are an inherent part of healthcare. In recent decades we have begun to uncover new ways [11] to implement these aspects of Satir's growth model in healthcare organizations.

Appreciative Inquiry

This approach developed by David Cooperrider [12] starts not with problems but with what an organization is already doing well. An excellent example comes from an intervention in an emergency room in Boston [13]. The patient satisfaction surveys from this unit were very poor. A problem-based approach would have focused on patients' main complaints and taken measures to correct them. An opposite approach was taken. Surveys of patients' satisfaction were fed back to staff but with all the negative comments deleted. So all that staff in the emergency room saw were the things that they were doing well. They were encouraged to do more of those maneuvers that were appreciated by patients. The results were a dramatic improvement in patient satisfaction. This approach does not address patient satisfaction as primarily a simple or complicated technical problem but a complex human problem in which the sense of competence and self-esteem produced by genuinely positive feedback provides the motivation and energy for the changes desired.

Self-Determination Theory

The effects of appreciative inquiry fit well with another development in positive psychology—self-determination theory [14]. According to this theory, there are three factors that affect whether people will change and embrace new behavior:

1. They need to feel competent to carry out the new activity.
2. They need to be genuinely involved in decisions with regard to implementing the new behavior.
3. They need to feel personally supported in carrying out the new behavior [11].

One can imagine that these two techniques (appreciative inquiry and self-determination) would mesh well together in producing a motivated and responsive working environment and they fit with another approach that sees expertise and growth coming primarily from bottom up rather than top down—positive deviance.

Positive Deviance

Positive deviance says that the expertise necessary to improve an organization and promote growth is already present within the organization [15]. What is needed is not primarily outside expertise but mechanisms to allow people within the organization who have on-the-ground experience to put their resources together to begin to suggest ways forward. One can imagine that these three approaches taken together can reinforce each other and facilitate a kind of development that would allow an organization to grow in a way that uses the best of what it already does, a motivated work force, and the expertise at the ground level to respond to the context in which it operates.

Whole Person Administration

One term for this new approach based on positive psychology to administration in healthcare and other fields is relationship-centered administration [16] because it is ultimately the relationships between people that determine growth in a complex organization. But the hierarchical model also has an important role to play. I believe there is an exact analogy here to curing and healing in medicine. Patients come to healthcare primarily to be cured just

as government and other funders will require clear-cut objectives, blueprints, detailed budgets, and deadlines from administrators—a hierarchical model of healthcare. Within that framework we need to put enough focus on relationship to create an organization that also harnesses the power of Satir’s growth model in embracing the value of individuals within an organization, their relationships, the complexity of the undertaking, and an openness to change. Will there be tensions between these two perspectives? Absolutely, just as there is tension between curing and healing in medicine. The ultimate test of a leader and an organization in healthcare is to find the balance between Satir’s hierarchical and growth models so that they synergize—very much like the job of a physician practicing whole person care for individual patients.

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Chapter 18

Healing Healthcare

*I am not a mechanism, an assembly of various sections.
And it is not because the mechanism is working wrongly,
that I am ill.
I am ill because of wounds to the soul, to the deep
emotional self
and the wounds to the soul take a long, long time,
only time can help
and patience, and a certain difficult repentance
long, difficult repentance, realization of life's mistake,
and the freeing oneself
from the endless repetition of the mistake
which mankind at large has chosen to sanctify.*

Healing, D.H. Lawrence

Lawrence's poem expresses well what I believe is needed in medicine as a whole. As in the poem, medicine is not simply "an assembly of various sections" but a human endeavor that is as old as man himself and aimed at addressing one of the great challenges of human life—suffering caused by disease. I believe that medicine does have a soul, and like the soul in Lawrence's poem, it needs to be healed, not by doing more of the same, however sanctified by society at large, but by what Toynbee would call withdrawal and return [1].

The Wound

The wound at the heart of medicine is very simple indeed. It is a disconnection between those administering care and the patients who receive care. When this central relationship fails, patients suffer and experience medicine as wounding and damaging, and healthcare practitioners experience burnout because they are not benefiting from the healing exchange that is an essential part of medical practice [2]. Paradoxically these very problems may be the opening for healing the soul of medicine because as Thomas Moore states, "Soul enters life from below, through the cracks, finding an opening into life at points where smooth functioning breaks down" [3, p. xiii]. And what is needed is not

to turn back the clock but to apply imagination [4, p. 26] to integrate the new gifts (and challenges) of medical progress with the most ancient aspect of medical care—the healing connection between doctor and patient [5].

The Challenges

There are different challenges that we face in healing healthcare that also represent much of what we are most proud of in our current system.

Medical Technology

There is no doubt that the development of medical technology has been staggering over the past 100 years. The technology of medical and surgical intervention has now been complemented by information technology that allows the rapid transfer of information about individual patients at the touch of a keyboard. These changes have produced results on the control and care of disease that have been revolutionary. However, they have done very little to benefit and very much to damage the relationships between doctors and patients. As Lewis Thomas pointed out some decades ago [6], doctors can now diagnose and treat their patients with very little human contact and sometimes no human contact. Histories can be obtained by an assistant or by the patients keying in responses to questions on a computer, lab results and imaging techniques have largely replaced the physical examination, and, in some specialties after a physician or surgeon has intervened to correct a problem, they may never again be seen by that patient in follow-up. This works well for the body as a machine but does not work well for the patient as a person. If Eric Cassell is correct and the cause of suffering is a threat to our sense of integrity as a person [7], then illness and disease represent the most acute form of such a threat and, more than anything, we need a human being to accompany and support us during this threatening experience. By creating a distance between patients and physicians, almost all medical technology hinders rather than helps the healing process.

Evidence and Data

Evidence and the data that provides evidence measure physical phenomena and actions. It does not by and large measure relationships. This is inevitable and not necessarily a problem unless we take the point of view not just that evidence is important but that it is the only basis for directing medical care. In such a

system, which is much of current medical care, a physician may be judged by how well the hemoglobin A1c is controlled in a diabetic [8] or whether she asked about the possibility of sexual abuse but she will not be scored on how much she cared about this patient or how well she established a healing relationship. To do so would be very difficult and perhaps it does not need to be measured. But in a system where only evidence and data count, the caring and relationship may be pushed aside by the concern with data and documentation.

Speed and Efficiency

In every phase of modern medical practice, speed and efficacy are measured and required. Whether it is length of stay in hospital or the time a physician takes to complete an outpatient visit or an emergency room consultation, there is considerable pressure to be quicker, which is taken as the equivalent to being more efficient. On the surgical wards of our hospitals, teams of residents and students do rapid ward rounds early in the morning before some of the team go to the operating room. To increase speed one person asks a series of questions that call for brief responses from the patient, while a second person notes down the results. They move rapidly from bed to bed, and patients who subsequently wish to ask follow-up questions after their turn has passed are generally brushed off. The team does not have time.

This is speed and efficiency of a certain kind, but it is not conducive to healing. Healing requires relationship [9] and relationship requires time, often unpredictable time. Sometimes the patient may be happy with the faster the better (most patients want to get out of hospital quickly), and at other times they may need a lot of time. It is not necessarily a question of going slowly but of listening and responding, with healing, rather than efficiency being the top priority.

When I worked at a palliative unit at one of our hospitals, I saw this contrast between a focus on efficiency versus healing in very clear terms. The contrast was all the more striking because this was a team whose main commitment and mandate were the healing of dying patients, and yet they were in a hospital where length of stay was measured and monitored. The problem would arise when a patient who was expected to die in 1–2 weeks (the average length of stay in the unit) would still be alive and doing relatively well after this 2-week period. The patient and family would normally be happy. The patient, whose transfer to the palliative care ward to die had usually been a major and frightening transition, was appreciative of the excellent care he was receiving, and he and the family often attributed his doing well to the ambiance and care at the unit. Imagine then the family's and the patient's unhappiness and often strongly expressed resistance when they

were told that they would have to be transferred again to yet another institution. This was clear-cut and major wounding to comply with a system devoted to efficiency and speed.

Control and Bureaucracy

The overriding concern of a large medical bureaucracy is the need to control the system. In the healthcare center to which I am attached, there is approximately one nonclinical administrator for every bed in the hospital [10, 11]. What are these bureaucrats doing? I do not have a complete answer to that question, but from a clinician's perspective, what they appear to be doing is monitoring clinical activity and making decisions about allocation of resources according to the data they collect and the objectives set by the administration. This is laudable as far as it goes but tends to make everyone more busy rather than less busy. What is needed is to create time and space for healing and that requires a very different sense of the mission of the healthcare mandate.

Medical Education

The first four challenges discussed above also play out in medical education. There is an increasing emphasis on control and bureaucracy with the intent of ensuring that all students are competent to a given standardized level. This process is facilitated by technology, particularly information technology, which makes the tracking of teaching and its outcomes relatively easy. Both implicitly and explicitly, we teach the importance of speed and efficiency. We are committed to evidence so that each teaching interaction must have clear and measurable objectives, which are then measured in a standardized way. The result is that our students are subjected to a process of continuous and repeated assessment. All of this is understandable and much of it is beneficial, but what is lacking is an equally powerful move to create sufficient space and time for students' individual growth and development.

The Solution

The above challenges are, however, not the problem. They are symptoms of the central issue: the loss of balance in healthcare. The increasingly external focus of medical practice and teaching has displaced a complementary

internal focus. Put another way, healing the soul of medicine and healthcare will mean making space for the interior resources and potential for growth that each individual patient and healthcare practitioner brings to their experience.

How should we proceed? We have made huge advances aided by the “challenges” enumerated above, and none of this progress needs to be abandoned. However, it is the interior processes of healing and growth in both the individual patient and the practitioner that give meaning to illness and to healthcare and are, and always have been, the beating heart of medical practice. We need to get in touch with that beating heart. To do so will take a profound change in healthcare, how caring is envisioned and how care is provided to patients. I hope that this book will prove helpful in catalyzing that necessary transformation.

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