Keynote Speech

Illness and Narrative

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My work for the last fifteen years has been built on three simple ideas.

First, the suffering of physical disease is made worse by social attitudes toward illness. Ill people are made doubly passive. They are treated as—and come to think of themselves as—*victims* of disease, and they are dehumanized by the medical treatments that are supposed to be caring for them. Of course not all medical treatment is dehumanizing, but too much of it is. A few weeks ago—August 16—the *New York Times*, the American newspaper that sets the agenda for other papers across North America, ran a front page story entitled, “In the Hospital, a Degrading Shift from Person to Patient.” As a commentary to numerous stories of how hospitals degrade patients, the article quotes extensively from Erving Goffman’s sociological classic, *Asylums*. What is extraordinary is that fieldwork Goffman did in the 1950s remains a relevant commentary to hospitals half a century later. I will not retell stories of how hospitals dehumanize; I assume such stories are familiar to all of you.

My second core idea is that if ill people are to hold onto their humanity, they need to find a story that gives meaning to their suffering. I take the word *meaning* from the classic work of Holocaust survivor and psychoanalyst Victor Frankl, expressed in his book *Man’s Search for Meaning*. As Frankl observed his fellow prisoners in Auschwitz and Dachau, he realized that those who survived had been able to retain a sense of *choice* in how they responded to their circumstances. Frankl writes: “everything can be taken from a man but one thing: the last of human freedoms—to choose one’s attitude in any given set of circumstances, to choose one's own way" (86). I would express Frankl's insight in terms of stories. The camp survivors chose to *tell their own story* about who they were and what their suffering meant. They lived this story in their actions, and their actions—such as sharing a crust of bread—became the story that sustained them. The lesson here is that *stories take care of people*.

Let me pause here and tell you a story of my own that illustrates how stories take care of people. In 1986 I was in chronic pain as a result of secondary tumors that were filling my abdomen and wrapping around the renal artery. The primary tumor was a testicular seminoma, and the physicians whom I was seeing were missing that diagnosis. While they tried to figure out what was wrong with me, I was in incredible pain, especially at night when I tried to lie down and that put pressure on my kidneys and the tumors. Very late one night I was wandering about our house, trying to make as little noise as possible so as not to wake my wife, but in great pain compounded by exhaustion. Then I saw something so beautiful that it lifted me out of my body. A large window was lightly frosted; outside it was a tree, and beyond that was a streetlight. The streetlight created a reflection of the tree on the window. In the frost, it looked like the finest etching. What made it especially beautiful was that I knew it was transient. As the temperature changed, the frost would become thicker and then melt; this painting had to be seen *right then*, because it was going to disappear.

Two thoughts immediately came to me. The first was that if it had not been for the pain I was in, I would have missed that beautiful image. My pain suddenly had purpose and meaning. Awful as that pain was, *it had put me in a place that I needed to be*, because something that deserved to be seen could be seen only by being exactly there, exactly then. The second thought was that all things are transient, and transience is all right. If that image on the window would change and then disappear, so could my life. As I thought this, my very real fears of bodily destruction lessened. I became part of an order of things beyond myself, and what was happening to me—my pain—mattered less.

My pain was still real, and my body was still in trouble. But I had taken one step toward regaining my humanity. In Victor Frankl's terms, I had regained some capacity for choice: in my case, the choice to see beauty and to find in it a relationship to my own situation. Thus I return to my core idea: *ill people need stories* that take care of them. These stories need not be complex narratives; in my case, an image on a window was sufficient. Stories restore people's sense of humanity, purpose, and meaning.

My third core idea is that there is professional work to be done—in both research and clinical practice—to give people a sense of the value of their own stories, to teach front-line clinicians the importance of witnessing and validating these stories, and to make it an institutional priority that clinicians spend time listening. Telling a story to yourself is a beginning, but for that story to have its fullest effect, someone else needs to witness it. People need to *hear themselves tell their own stories*, and this requires a listener. The listener becomes a *witness* when she or he displays recognition of the story's significance and value. To be a witness is to show a storyteller that all the world depends on that story—just as my whole world depended on that window.

The professional's task is *not* to tell people what stories ought to be significant for them. People have to *find their own stories*; the stories they find for themselves—as I found my story of the frosted window—are those that can take care of them best. But what clinicians and researchers can do is to *amplify and spread* people's stories. Professionals can *connect* people through their stories. Researchers and clinicians can spread good stories, which can show people how they might tell their own stories.

As professionals, we have an extraordinary privilege of being able to speak in public and publish. We can use this privilege to *amplify* voices that would not otherwise be heard, thus performing a public act of witness that can change the understanding of illness in a society. This change will not be rapid or widespread, but it will be real, nevertheless. The possibility of telling new stories can, I believe, change the world. In fact, I think that new stories are the principle way in which the world changes, for good and for bad.

Those are my three core ideas. First, that the physical suffering of disease is increased by the social suffering of turning ill people into dehumanized victims. Second, that people need stories to regain their sense of humanity. And third, that there is professional work not in *analyzing* ill people's stories, but in demonstrating their importance and *amplifying* their voices.

I want now to summarize how I approached this work during the mid-1990s, especially in my second book, *The Wounded Storyteller*. After that, the final part of my talk will suggest my work in progress on what I call the dramas of illness.

After I had written my first book, *At the Will of the Body*, which is my own story of my illnesses and has been translated into Japanese, I began to read many other people's stories of their illnesses, and a number of these books were published in the early to mid 1990s. My main interest was in how I could help clinicians appreciate the importance of ill people's stories, and how I could help ill people understand the ways their stories were shaped by the narrative conventions of North American society. I believe that people tell their own stories, but people do not make up, by themselves, how to tell these stories. We each speak our own thoughts, but we speak in a syntax and vocabulary that language provides, and we do not make this language up ourselves. Just as our self-expression is constrained by syntax and vocabulary, so our storytelling ability is constrained by what *narrative templates* a society makes available for us. Any culture, at any given time, has a certain number of these narrative templates. To be able to tell a story—to get the story told and make it intelligible to others—a speaker has to use one of these available narrative templates.

What I tried to identify in *The Wounded Storyteller* were three core narrative templates in which stories about illness can be told, or could be told in North America in the 1990s. I emphasize that narrative templates are relevant in particular cultural locations, at particular times. Some narratives travel cross-culturally, but how people tell stories is specific to their cultural locations. Thus, the narrative templates I located in my time and place—North America in the 1990s—will have to change when thinking about Japan today, and I leave to you the work of describing the current templates for telling illness stories in Japan.

The first template sets out what I called *restitution* narratives. These stories idealize the goal of *restoring* people to life before illness. I first clearly recognized the restitution narrative when I happened to read a hospital advertising brochure that described six or seven patients who had received cancer treatment in their hospital. Each patient's story followed the same narrative: the person had been living life full of activity; then she or he gets cancer and is treated in the hospital. The stories all ended with the person now back to his or her original activities—the life she or had before illness was restored after illness.

The restitution narrative is intelligible and has appeal because it contains resonances—echoes—of some very old stories, especially the story of Job in the Hebrew Bible. Job is a righteous man who is tested by God: he loses his family and his wealth and suffers terrible disease. At the end, God restores to Job all that he lost: his health, wealth, and family. That narrative of loss and restoration is familiar and available, and contemporary medicine has picked it up as its preferred narrative of illness. This is the story that cancer patients are encouraged to tell about themselves; or to be more precise, *restitution* is the narrative template within which individual stories are to be told.

Social pressures to tell restitution stories are very real. After I had finished chemotherapy, people we knew would say to my wife: "He's all right now," *not* as a question, but a statement that she was expected to affirm. Her work was to uphold their story that even terrible illnesses can end in restitution of life as it had been. A significant part of the *emotion work* that ill people are expected to do is to keep safe the worlds of healthy people who fear illness. That emotion work is draining and oppressive to the ill and their families, because it often requires denial of the realities of their lives.

When medical workers become caught up in restitution stories, they can imagine only new forms of treatment, even if those treatments are futile. People caught up in restitution become unable to see that they are failing to offer what those who suffer truly need—*care* in the sense of comfort and recognition. During the last decade there has been substantial change, with medical workers increasingly willing to recognize futility and reject it. But many remain stuck in restitution narratives. When treatment is rejected as futile, too many medical workers find it difficult to express on-going care. They simply have no story that guides their actions, once the restitution story can no longer be told.

My second narrative template is the *chaos* narrative. Chaos stories are actually *anti*-narratives, in this sense. In a narrative, one thing leads to something that follows from it; narratives progress, through time and space, from a beginning to an ending. The literary scholar Frank Kermode wrote a well-known book called *The Sense of an Ending*, and it is crucial to a narrative that the actions lead to some kind of resolution that provides the sense of an ending. In chaos narratives, one thing happens after another, but nothing *leads* to anything else; there is no ordering of events, and that is what is chaotic. No ending, in the sense of a resolution, is in sight.

In chaos narratives of illness, a new symptom appears or old symptoms intensify, another member of the family becomes ill or injured, some property is damaged, an insurance or welfare benefit is withdrawn—and, crucially, *nothing can be done* to stop this progression of disasters. The person living the chaos narrative is defeated by life, and as this person describes his or her life in chaos stories, everyone around them comes to feel defeated. Persons caring for such patients come to believe that if they spend too much time listening, they too will be pulled into the chaos, because its pull is powerful. Thus people withdraw from the person living and telling the chaos narrative, and those withdrawals become a further part of the chaos.

I have no easy answer of how to respond to people living and telling chaos stories. Two points seem important. The first is *not* to try to fix the chaos, although that will be the first reaction of most clinicians. Some people's lives are deeply chaotic and will not be fixed, at least quickly. The person living the chaos story will see others' attempts at fixing not as help but as their own self-protection against what the clinicians find frightening. Thus the second important point of response is for the clinician to show that she or he can *stay in the room* with the chaos and not be destroyed by it. The person living in chaos has a dark fantasy—not without elements of reality—of their own destruction, and the first, significant response of the clinician is to demonstrate that it is possible to enter the chaos and *not* be destroyed. The clinician can model the possibility of moving in and out of chaos and learning to reflect on it, rather than being immersed in it.

Chaos narratives present suffering as being without purpose or design; as I said, they are stories without narrative structure. My third type of narrative, *quests*, resonate with humanity's oldest narrative structure, the heroic epic of call, descent, suffering, return, and at the end, some reward for suffering, either a material reward or a spiritual one. My story of being in pain and then seeing the beautiful frosted window was a quest narrative: the symptoms were the *call*; I *descended* into sleeplessness; I *suffered* pain but that suffering had some turning point; in the insights I felt on seeing the window, I began a *return*, and in the transformation of my suffering a received a kind of *reward*.

People tell quest stories when they say that despite all the suffering, they can appreciate what their disease has brought to their lives. More important, people who have experienced some self-transformation through illness want to share this with others. Thus in quest narratives, illness and suffering becomes sources of insight that the ill person understands the world as needing. The quest is to tell the healthy world truths that can be learned only through illness. Almost all published illness narratives, and most of the stories that appear in newsletters of support groups, are quest narratives. The reality of loss is not forgotten, but it becomes secondary to what has been gained.

In quest narratives, the person expresses an inability to imagine his or her life without having had the illness, although life after illness is anything but restitution. The nature of the experience means that the person lives a new life, or lives a new version of his or her old life. Again, the emphasis is on transformation, growth, development, and how personal change can institute broader social change. People telling quest stories have a mission, which is to tell the story, because that story can change the course of suffering for those who will come after. Unlike the restitution story that imagines doing away with suffering, the quest story works to accept the inevitability of suffering. Telling quest stories helps others to move more quickly to the insights that suffering can offer.

In the decade since I wrote *The Wounded Storyteller*, many researchers and clinicians have used these three narratives as a typology within which to organize observations. In a recent issue of the journal *Social Science & Medicine*, the British researchers Brett Smith and Andrew Sparkes use these three narrative types to understand the experiences of professional athletes whose careers are ended by debilitating spinal cord injuries. Smith and Sparkes are especially interested in the dynamics of hope among these men. Hope, they observe, is always situated in a story about a possible future. Let me leave these applications of my three narrative types, and turn now to the ideas I am currently developing about the inherent drama of illness.

I believe that in any serious illness, or trauma, or chronic condition, at least *five dramas* are taking place. The study of these dramas is both clinical work and a research program, so I will focus on *core questions* that can be used to open stories in which the drama can develop. Dramas are *dramatic*: something is at *risk*. Both clinical and research questions not only ask *about* this drama, they claim the questioner's recognition of the drama and his or her *participation* in it. Thus the questions must be asked with *suspense* based on intense *caring* about what will happen to the hero of the story who is also the storyteller. That caring includes a willingness to *imagine* life as the storyteller depicts it, and the imagination of that person's life increases caring.

I. *The drama of genesis.*

I take the importance of *genesis* especially from sociologist Gareth Williams' classic study of the stories that people with advanced rheumatoid arthritis told about how they believed their illness had originated. Genesis stories trace illness or trauma to what someone did or what was done to them. Williams reports how one person explained the genesis of her illness by telling a *psychological* narrative that traced illness to her personality. Another constructed a *theodicy* in which God was testing her. A third told a *political* narrative about capitalist exploitation in the form of his exposure to toxic chemicals in different work sites. Each genesis creates its own *tension* of forces; the sufferer must align him- or herself among these forces.

Both the research and clinical response to these stories is not their adequacy as explanations of the person's disease. Rather, the issue is how these stories take care of the people who tell them; how the stories endow the ill person's life with a sense of drama that *makes that life a story worth living*, despite all the ways it is painful to live. Here is Victor Frankl's sense of *meaning*: people can survive suffering when they have a sense of living out a story that is *worth* living; when, that is, they take seriously what is at stake in the clash of forces, and they see themselves having a *role in the outcome* of this clash. The story—which represents the forces at odds with each other—is the *idiom* in which the patient is doing the *work* of suffering.

Core questions to both patients and research participants:

- How do you believe [this condition] *began*? What caused your disease?
- How has that beginning made a *difference* in which ways you found to live with [the condition]?

- How has that beginning made a difference in whether certain treatments were more or less effective?
- Where does that sense of a beginning *lead* you, as you think about your future life with [this condition]? What *tasks* does that beginning set in place for you?

In asking these and other questions, clinicians and researchers need to prepare for the questions by assuring the patient or participant that the clinician/researcher is *not already committed* to one particular explanation. Nor will the first story that the patient/participant tells about genesis be their eventual story. In illness stories as in *all* stories, there is uncertainty about *where the story begins*; most genesis stories lead back to preceding stories. As stories are told, one story leads to anther, and *the beginning place will probably change*. That change does not reflect inaccuracy in the former story; stories *co-evolve*, and the objective is to observe and participate in that evolution.

In the telling of genesis stories people are often best able to express two central features of suffering: *resentments* and *tasks*. Most suffering involves resentments: against one's heredity, or the environment, or working conditions, or medicine, or God. I accept the Freudian view that resentments not expressed openly will express themselves in displaced forms, including self-destructive acts. Genesis stories also set in place the tasks that the person needs to undertake to repair some original rift, or loss, or split that the genesis story describes. I find it more useful to think of *tasks* than the more frequently invoked notion of *hope*. *Tasks* can be broken down into small pieces, and stories about accomplishing those small pieces keeps the bigger illness story fluid and flexible. *Hope* risks fixing the story on one desired end-state that may or may not happen.

II. ***The drama of emotion work.***

I take the idea of "emotion work" from the seminal research of sociologist Arlie Hochschild on jobs—from flight attendants to grocery checkout clerks—that require a particular emotional self-presentation as part of the work. Being a patient requires emotion work, because most patients—I would say *all* that I have ever met—fear alienating clinicians who could impede their access to medical resources, and they fear alienating friends, family, and work associates from whom they need support. I have *never* spoken with a patient support group in which someone did not talk about this need to modulate emotional responses to fit others' expectations, with other group members assenting.

A great story of emotion work is told the set of notes left by the 19th century French novelist Alphonse Daudet, who lived in extreme pain caused by tertiary syphilis. Daudet's secretary describes him sitting in great pain one moment, then on his feet and laughing when his wife enters the room, and collapsing back into his chair when she leaves. "Suffering is nothing," Daudet is quoted as saying, "It's all a matter of preventing those you love from suffering" (x). That is the most selfless side of emotion work, as opposed to the self-protective side.

Core questions:

- Who else is affected by your pain/disease?
- Do you feel you protect them? *Tell a story of that protection.*
- If you could, how would you like to be able to protect them?
- Do you feel they are working to protect you?
- And then the more difficult questions for clinicians to ask: What effort does it *cost you* to be here, in this clinical setting, to be treated? What is the drain on your energies, being here?

These latter questions that reflect on the clinic itself have to be taken slowly, as the patient feels safe telling the truth. Clinicians exploring this area will also be doing their own emotion work, and here, especially, the asymmetry of the storytelling is consequential. The story is co-created, but it's a story to take care of the patient, at least primarily. The clinician may need someone else to witness the stories of his or her emotion work.

III. *The drama of faith and desire.*

Humans have the particular capacity to interpret suffering with an awareness of some purpose or dimension that *transcends the self*. How people understand this self-transcendence and what language they express it in are as variable as they are sensitive.

The *core questions* begin with *exploring what language* a person is comfortable with: traditional religious terms, the "ultimate concern" described by existential theologians, the "higher power" of recovery groups, or Western adaptations of Eastern religions, for example, mindfulness. The choice of language is crucial. One vocabulary will shut down conversation, and another can enable stories to be told. Questions begin with this choice of language.

I pair faith and desire together because a *core question* might be: What purposes give your life value? Or conversely, what values give you a sense of purpose?

In some people's story, values and purposes can be quite secular, yet be upheld with a force that can be called faith. Another rheumatoid arthritis patient interviewed by Gareth Williams, Mrs. Fields, organized her life around what Williams calls her three *virtues*: maintaining a degree of physical independence, financial solvency, and cleanliness in her person and her home. Those virtues gave Mrs. Fields' life meaning because they were expressions to relationships that took her beyond herself. Her actions expressed her responsibility to, and need for recognition from, her adult son and the visiting nurses who came to care for her. Mrs. Fields' virtues are utterly mundane, yet as she works daily and hourly to express them, they give her life transcendence in the sense of aspiring to sustain something *beyond* her self.

IV. *The drama of fear.*

The pleasure of ghost stories lies in knowing we can walk back out of them. The claustrophobic suffering of disease and pain is their inescapability. The dark side of stories is that they can entrap us in imaginations of what we find most frightening; our stories can impose a future horror on the present. Thus in the drama of fear, it is often necessary to *get out of stories* that a person is telling him or herself. But the paradox is: to get out of a story, it's usually necessary to tell that story, giving fear its fullest expression. Again, people need to hear themselves telling their own stories, but in this case, the objective is to get out of those stories, or at least to move them from fantasies to realistic risk appraisals. Most often, a fear has to be validated as truly fearful before a new future story can be told that diffuses that fear. Here as elsewhere, the crucial clinical task is *not to challenge the story* but to work with it, so that it can evolve into a new story.

Core questions:

- What about your present situation do you find most frightening?
- What possible future frightens you?
- What other illness stories have you heard that you found frightening?
- Among those things about your life that you value most, what are you afraid of losing?
- The limit of these questions is that the greatest fears are unspeakable; repeated stories can move them toward articulation, giving them metaphoric form. In research interviewing, repeated interviews are certainly preferable, so that changes in the story can be observed.

V. ***The Drama of Self and Solidarity.***

Core questions.

- How has illness [pain] threatened the person whom you were; what aspects of that person have been most affected?
- After living with illness for [whatever period of time], what can you see or feel today that was not part of your life before illness?
- How has illness affected your *relationships* with others?
- What relationships have been damaged or lost? What new relationships have been formed, or what old relationships have expanded?
- With which other people do you feel a new identification or solidarity? How does that identification or solidarity affect your sense of who you are?

In these questions, the objectives of clinical work and research seem not so different: both aspire to see others *in their true form*, which requires a relationship of mutual assistance. Both clinical work and research interviewing are also means through which ill people can come to see *themselves* in their true form.

A powerful metaphor of true forms occurs at the end of Margaret Edson's drama *Wit*, which was first a play and then a film. *Wit* is about the last year in the life of a woman dying from ovarian cancer. At the moment of her death, the hero sheds the material trappings of illness. The stage directions read: "She walks away from the scene, toward a little light. She is now attentive and eager, moving slowly toward the light. She takes off her cap and lets it drop. She slips off her bracelet. She loosens the ties and the top gown slides to the floor. She lets the second gown fall. The instant she is naked, and beautiful, reaching for the light—Lights out." The constant aspiration of both ill people and medical workers is to see each other, and see themselves, in that light *while* the illness is going on. Research can amplify and spread stories in which people achieve some degree of this vision of themselves and of each other.

As a sort of conclusion, let me add five notes or caveats to the practice of responding to illness as comprising these five dramas.

First, *no drama precedes* any other, so where to begin storytelling involves making a judgment of where the patient or research participant is *ready* to begin. If one beginning is not opening up stories, try somewhere else. All the dramas are taking place, but not all are ready for storytelling, and not all stories are ready to be shared. And of course the five dramas I have suggested by no means exhaust the scope of the stories that can be told and need to be told. This template is nothing more than a beginning.

Second, these dramas are best explored over a *period of time*. To explore more than one drama in one clinical encounter or research interview would be overwhelming. The point is for stories to *co-evolve*.

Third, and relevant to clinical work, while some institutional commitment of real time is required, much narrative work can be done during otherwise unfocused moments of mundane medical care. Short bits of time are what matter, over an extended period. The real institutional commitment required for this practice is to *continuity of care*. Narrative medicine depends on relationships within which stories are co-created and co-evolve; the nature of relationships is to require continuity. The payoff for this continuity will be multiple, from less staff burnout to greater patient adherence. In the briefest terms: everyone does better when they look forward to seeing each other, and people who are co-evolving a story want to know where that story goes next.

Fourth, as I said earlier, questions should be asked as openings to a drama, in which the clinician or researcher is playing a part. The best advice is: *See yourself not as the director of this drama, but as a player in it.* Listen with suspense based on imagination and caring.

Fifth and finally, questions must be asked *recursively*, as stories develop and weave together. Recursive questioning means asking the same question again, at a later time, with a recognition that now it is a different question—eliciting different stories—because the relationship has developed since the earlier asking of the question.

The weave is complex in which one story leads to another, and one story depends on another for its understanding. Narrative work understands that in some of life’s most important undertakings, you get where you’re going by returning, repeatedly, to the beginning. In most myths and folk tales, the hero comes to realize that she or he has never really left the starting place; thus T.S. Eliot’s great lines about returning to where we began and knowing the place for the first time. In any story that is well entered into, we find ourselves in a place we always have known, but we are aware that we are knowing it for the first time.

Photo. Dr. Frank (left), Dr. Sato (center) and Ms. Mitachi (oral translator, right)