

CHAPTER TWO

Just Listening: Narrative and Deep Illness

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*For seven days and seven nights [Job's friends] ...
sat beside him on the ground, and none of them
spoke a word to him, for they saw that his suffering
was very great.*

Job 2:13

This essay is about the stories told by those whom I have come to call the “deeply” ill. Deep illness may be critical or chronic, immediately life-threatening or long-term. Levels of functional impairment vary: some of the deeply ill are seriously disabled, in pain, and require intense and constant medical treatment. Others are in stable remission, with their illnesses effectively invisible to strangers and even to work associates. What counts is the person’s own perception of illness: Illness is “deep” when perceived as lasting, as affecting virtually all life choices and decisions, and as altering identity. The essence of deep illness is to be *always there* for the ill person, and the person believes it always will be there. If illness moves temporarily to the background of awareness, that shift is only provisional.

For as long as one is deeply ill, there is no end in sight. Deep illness is lived in the certainty that it will be permanent and with the fear of this permanence. Some of the deeply ill have every assurance that they will be ill for the rest of their lives. Others have some chance of recovery, possibly a good chance, but illness is deep as long as any light *they* can see at the end of the tunnel is, at best, flickering. Whether someone remains deeply ill while in remission from cancer or while enjoying a good prognosis following successful heart surgery is a matter of that person’s subjective interpretation of her or his situation. Between two and three years after my own treatment for cancer ended, I realized I was referring to myself as someone who had *had* cancer, rather than someone living *with* cancer. I had imperceptibly moved out of deep illness, and the shift bore little relation to a medical definition of remission.

The Need for Stories

Several recent studies have described the ill as storytellers (Frank, 1995; Good, Brodwin, Good, & Kleinman, 1992; Hawkins, 1993; Kleinman, 1988). The clinical importance of ill people's stories can be framed between two quotations. The first is from psychiatrist and medical anthropologist Arthur Kleinman. After noting that "physicians do not routinely inquire into the meanings of illness," Kleinman (1988) argues that "a powerful therapeutic alternative is at hand":

There is evidence to indicate that through examining the particular significances of a person's illness it is possible to break the vicious cycles that amplify distress. The interpretation of illness meanings can also contribute to the provision of more effective care. ... This key clinical task may even liberate sufferers and practitioners from the oppressive iron cage imposed by a too intensely morbid preoccupation with painful bodily processes and a too technically narrow and therefore dehumanizing vision of treatment, respectively. (p. 91)

Kleinman emphasizes "empathic witnessing ... of the patient's and family's stories of the illness" as central to clinical work (p. 10).

Kleinman's emphasis is strategically placed on clinical efficacy. As a professor of medicine, he seeks to convince his colleagues and his students to allocate time, first in the curriculum and then in practice, to attending to the stories in which patients reveal the meanings they attach to their suffering. My own concern is less with the *patient* — the object of medical attention and intervention — and more with the *ill person* — the one who is struggling to negotiate a life lived in deep illness. Thus I balance Kleinman's statement with a different voice, that of the physician Rachel Naomi Remen.

Remen works with persons who have cancer, offering them not medical treatment but empathic attention. Kleinman advocates attending to stories as a functional part of clinical work. Remen moves outside her physician role self-consciously placing herself as another who is wounded (see Remen, 1994, 1996). She makes attention an end in itself:

Being here [in the Commonwealth retreat program] opens up opportunities for people to be listened to, and heard, and validated. They're not stuck anymore. If you ask, "How does that happen?" I have to say I'm not sure — but it does, and I trust that. I think the greatest thing you can ever give someone else is your attention — not with judgment, but just listening. (Quoted in Moyers, 1993, p. 345)

No great distance divides these two quotations. Both Kleinman and Remen clearly emphasize that stories count not just for the ill person but also for the healthcare professional who, as Kleinman states so powerfully, also suffers within an “iron cage” of reductive concerns.¹ Those who care for the ill also have their own stories (Hunter, 1991; Kleinman, 1988, pp. 209–226; Williams, 1984). In the most interesting and recent of these narratives (Campo, 1997; Hilfiker, 1994), physicians suggest that their capacity to know their own stories depends on the extent that they can hear the ill. For professional care-givers to be persons to themselves, they must first see and attend to the persons who are their patients.²

On the benefits of attending to the voices of the deeply ill, let me add a third voice — my own. I study the stories of the ill because when I was in the midst of my own period of deep illness — first heart attack, then cancer (Frank, 1991) — I longed for healthcare professionals who would “audit empathically” (Kleinman, 1988, p. 17) the story that *I could not tell unless they listened*. A story needs a listener. I needed their gift of listening in order to make my suffering a relationship between *us*, instead of an iron cage around *me*. Thus I first came to the concerns expressed in this essay by seeking to express what I needed when I was ill.

Professional Use of Narratives

The importance of listening to ill people’s stories should be qualified by a reservation about professionals taking up listening as a routine task. When listening becomes a task, instead of what Remen calls a gift, then I believe much of its therapeutic efficacy is lost. When “narrative” becomes another professional technique for assessment, diagnosis, and intervention, then what Kleinman and Remen value in listening becomes part of a routine and is experienced as such. Narrative reduced to *clinical technique* leaves both clinician and patient inside Kleinman’s iron cage of reductionism.

What Kleinman and Remen point toward, and what I wanted when I was ill, is a mutual relationship of persons who are also clinician and patient. Stories that are shared among persons can open mutual relationships; narrative reduced

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1. Non-social scientist readers may miss Kleinman’s allusion to the German historian Max Weber who, in 1905, concluded *The Protestant Ethic and the Spirit of Capitalism* with the condemnation that capitalist acquisition had become an “iron cage” in an age of “specialists without spirit.” This allusion broadens Kleinman’s critique to how society has created an institution of medicine that mirrors its own values.
 2. On physicians’ narratives, see Frank, 1997b.

to clinical technique may or may not be an improvement over biomedical reductionism.

When I as an ill person offer someone my story, I reach out as one human being to another. Stories certainly have content: they reveal the meanings that the ill have constructed around their illnesses. But telling the story also implies a *relationship* that I desire with those who care for me. For others to respond as if my story has not touched their personal core separates the content of my story from my desire for a relationship. Content then becomes “clinical material,” and the gesture toward relationship is implicitly refused. Clinicians who attend to the meanings that stories reveal while rejecting the relationships that telling offers adopt a contradictory stance that will affect any future therapeutic relation.

The potential of narrative is to reorient our understanding of therapeutic relationships, but until this reorientation is effected, “therapy” can be a misleading word when coupled with narrative. Exchanging stories fractures the asymmetrical, dualistic assumptions of most doctor/patient or therapist/client relationships. Clinical relationships are too often between subjects-who-know and objects-who-are-to-be-known. The story, to be worth that name, is a ground on which subjectivities meet in *mutual* knowing. This fundamental human need is to know and to be known. Parker Palmer (1993) adapts a line from *1 Corinthians 13* as the title of his book on educational relationships: *To Know As We Are Known*. This title could serve equally well as an ideal of clinical practice and a basis for revising clinical training.

Physicians and other professionals — I include myself as a university teacher — do not routinely take seriously our own *need to be known* as part of the clinical relationship. Yet unless the professional acknowledges this need, the client remains the object of the professional’s privileged subjectivity; there is no relationship in the sense of reciprocated feeling for the other, only an interaction.³ The pressure of being the one who is supposed to know is, of course, as enormous as it is isolating. By contrast, knowing and being known each supports the other.

The rest of this essay will describe the stories told by the deeply ill, with the understanding that these stories are *not* being attended to as objects for chart notation or as justifications for interventions. Instead, professionals hear stories to know as they are known. An inextricable relation exists between knowing the other, being known by the other, and knowing oneself. When this relation is

3. In a period of “managed care,” professionals’ motivation to know the other in a way that excludes being known by that other may have less to do with professional socialization or with personal desires for control and distance, and more to do with institutional demands for “productivity.” Clinical encounters are overdetermined by institutional, professional, and personal factors.

forgotten, attention ceases to be a gift and becomes reduced to instrumental necessity; both parties find themselves back inside the iron cage.

One last loop needs to be thrown into the argument. Having argued for the necessary mutuality of storytelling — that it is a gift relation, not a professional technique — I need to add that, within the clinical relationship, a *hierarchy of needs* exists. The deeply ill person is the immediately needy one, and this person's story deserves primary attention. Clinicians may share parts of their own stories, but they do so in response to the ill person's story. Reciprocity is sustained in the appreciation with which the clinician receives the patient's stories. To give the gift of listening is to appreciate receiving the gift of a story. Not just understanding this reciprocity but *embracing* it seems to me to be the beginning of clinical work.

What stories, then, do the ill tell? I propose three basic *narrative types* of illness stories. These are not specific stories but types of stories. Folklorists throughout this century have pointed out the basic narrative structures that underlie many particular tales. Children learn these narrative forms without knowing they know them, and they then use them both to make sense of new stories and to improvise stories of their own. Folk tales require a hero, or more accurately, a protagonist, who will become a hero in the course of the story. The hero then seeks something, and the seeking is blocked by some antagonist. The eventual defeat of the antagonist is often made possible by a helper who at first appears minor and ineffectual but eventually provides the hero with an essential resource. On the bare bones of such narrative skeletons, many different stories are fleshed out. Oral storytelling in particular requires some recognizable narrative structure if listeners are to find their way through the story.

What I present below are three recognizable narrative structures — the skeletons on which many stories of illness are fleshed out. To grasp the uniqueness of stories as they are told, it helps to be able to place a story in relation to others: how does the immediate story build on the skeleton(s) it shares with other stories? These three narrative structures also help to hear what is not being told in any particular story. I propose these three narratives not as privileged professional categories for decoding and classifying stories. Again, stories are not material to be analyzed; they are relationships to be entered. But staying with a story can be like finding a usable pathway through a thicket. I intend these three narratives to be such usable pathways. As others leave my pathways and find their own, they and those they listen to will be served all the better. But these pathways can at least be ways of entering.

The Restitution Story

The narrative of illness that is culturally preferred in North America tells of getting sick, suffering, being treated, and through treatment being restored to health.⁴ When the ill person's answer to "How are you?" is to repeat everything that treatment has already done, is doing, and will be able to do if the present efforts fail, then a restitution story is being told. On closer listening, it is possible to hear an absence: the subjectivity of the ill person who is telling the story has been displaced by others. The clinicians — physicians, nurses, and therapists of all sorts — are the heroes, the active players in the story; their subjectivities determine the course of the action. Restitution stories are told by ill people who narrate from the sidelines.

Restitution stories predominate in the talk of the recently diagnosed, and the ideal of restitution recedes farthest into the background of stories of chronically ill persons. Few published illness stories follow the restitution narrative: in the logic of restitution, illness is nothing in particular to talk about once one is cured. The conventional pejorative label for such talk is "dwelling on it." Restitution stories are better told by physicians themselves, in their own journals.⁵

Restitution stories are expected and encouraged by the most scientific (and "heroic") versions of medical practice. Because disease is an enemy and cure is a version of conquering that enemy, the notion of talking about illness as *meaningful* experience seems superfluous — even vaguely subversive — to biomedicine. In the biomedical model, patients' talk *should be* second-hand medical talk: close enough to the physician's version to insure compliance with medical orders, but not so close as to suggest patients might make their own treatment decisions.

Because most illness conditions will end in the restoration of health, for most ill people the restitution narrative is adequate. Problems arise as soon as restitution is no longer perceived as forthcoming: when the persistent cough turns out to be lung cancer or the problem of balance is diagnosed as multiple sclerosis. My own testicular cancer was first diagnosed as a urinary tract infection and

4. The three types of narrative — restitution, chaos, and quest — are described with extensive examples in Frank, 1995, chapters 4–6. In this essay, I have minimized examples in favor of a more programmatic exposition.

5. I retain this paragraph even though the Internet seems to be providing a venue for the proliferation of written, if not published, stories that are strongly oriented toward cure and medical intervention. When ill people use their own web sites to marshal medical information and resources, they become the protagonists of their own restitution stories. Physician dislike of patients' posting their medical progress — and bringing the responses they get back to the clinic with demands for treatment — remains anecdotal (see McLellan, 1997).

treated with antibiotics; for the weeks until my symptoms intensified, restitution stories made good sense. But when those drugs failed to have any effect, I had no narrative I could use to tell the story of my deterioration.

My lack of a narrative that could make sense of my decline into deep illness was not a personal shortcoming of mine nor of my physician. North Americans are culturally deficient in narratives to tell after the restitution narrative no longer applies. What Kleinman calls the “vicious cycles that amplify distress” are cycles of *narrative lack*: when people have no story to tell, they are isolated in their suffering; they can achieve no critical distance from their pain. Other narratives — those described below — are available, but too many healthy people — and too many clinicians — do not attend to them. These other narratives are disregarded until we need them, which for those who are ill means needing them yesterday.

I hardly want to deprecate restitution stories. The restitution narrative represents the triumphant optimism of medical science — a science that has saved my own life — and commitment to the idea of cure deserves to be honored. The problem occurs when we love the idea of restitution to the point of demonizing illness. When we believe that no other narratives are legitimate, we then pathologize other stories as depressing (a lay epithet) or as symptoms of depression (the professional analog). The deeply ill, whose immediate reality does not include restitution, are further marginalized. Those who have no story that society judges worth telling feel they have no place in society.

The Chaos Story

Diametrically opposed to the restitution narrative is the chaos narrative. Here is deepest illness: disability can only increase, pain will never remit, physicians are either unable to understand what is wrong or unable to treat it successfully. Medical problems proliferate into social problems: persistent ill health means job problems, which mean loss of income, which leads to inadequate medical care. The ill person is shuffled between bureaucracies, each claiming that they need something from somewhere else before they can provide any benefits. Stress exacerbates medical problems. Family responsibilities cannot be fulfilled: social ties are lost, and the ties that remain are often more demanding of the ill person than they are supportive.

Chaos stories can be heard most clearly in the responses they elicit in listeners: when the listener feels sucked into a whirlpool and only wants to get away from the story, then a chaos story is being told. If the dominant verbal style of restitution stories is quotation from the clinician, the dominant style of chaos stories is a series of incomplete sentences. Actions end with a shrug, not an object of the verb. To complete a sentence is to imply a world in which subjects can act on objects and have some effect. The world of the chaos story is devoid of effective action. The passive voice reigns: “it” affects the teller. Events take place

in a perpetual present tense punctuated by “and then” constructions: “and then” the physical problem, “and then” the family problem, “and then” the bureaucratic hassle, and then how each of these makes the others all the more unresolvable.

Chaos stories reflect life lived at the bottom of the funnel of these problems. People live chaos, but chaos cannot in its purest form be *told*. To talk from the position of chaos is to be unable to render one’s life as a story with any narrative ordering of beginning, middle, and (anticipated) end: the story perpetually trails off in a formless sequence of “and then” contingencies. To tell enables achieving a coherent stance as to what took place and why. The coherence that stories give to lived reality, along with the effect of sharing the story with a listener, offers the teller some distance from his or her life. The chaos talk that cannot become a story induces claustrophobia in the listener because of its lack of any distance from immediate events. Chaos talk is submerged, gasping for air, and it soon leaves the listener gasping.

To turn a life lived in chaos into a story *about* that chaos would effect a transitory escape: at least a crack of light shines into a room that was entirely dark. Paradoxically then, the chaos story that can be told is no longer total chaos, and in that paradox lies a therapeutic opening. The clinical problem is not to push toward this opening prematurely. The chaos narrative is already populated with others telling the ill person that “it can’t be that bad,” “there’s always someone worse off,” “don’t give up hope,” and other statements that ill people often hear as allowing those who have nothing to offer to feel as if they have offered something.

If our culture loves the restitution narrative that any illness can be cured, it fears the chaos narrative that, with illness, troubles multiply. The chaos narrative (that cannot be told) is about how thin the ice is upon which we skate, and how cold and deep is the water into which we can suddenly sink. In my undergraduate medical sociology course I show a film about a young man who discovers he has a rare adrenal cancer. In response to the film a student wrote that he had never before realized how suddenly he himself — anyone — might have a life-threatening illness. By keeping the recognition of serious illness out of his conscious awareness, my student had enjoyed what might be called *deep health*. The chaos narrative — with its vision of how awful life can get — threatens deep health.

To deny the living truth of the chaos narrative is to intensify the suffering of those who live this narrative. The problem is how to honor the telling of chaos while leaving open a possibility of change; to accept the reality of what is told without accepting its fatalism. Sustaining this delicate balance requires, at minimum, not being overwhelmed by the need to *do* something for the ill person. If it were easy to change that person’s situation, others probably would have done so. Any change will take time; thus, with the deeply ill, change is a problematic goal. What kind of change may be appropriate is a difficult issue on which the professional must be constantly guided by the ill person and his or her family. The first thing a person in chaos needs is someone who will just listen, without

attempting any change. Too quick offers of help may show the listener's own dis-ease with what is being told; compassion means, literally, to suffer *with* the other.

Job's three friends first sat with him in silence for seven days and nights. They became less useful when they began asserting their own answers to his question of why he suffered. When Job eventually finds an answer to his suffering, it is not one that admits articulation. The measure of his wisdom is his new capacity for silence.⁶

As a society, our problem is how to honor the suffering that the chaos narrative implies without accepting the remediable conditions — the lack of care — that perpetuate this suffering. Primary among these remediable conditions is the professional and lay tendency to pathologize chaos: to label the ill person as “depressed” rather than to accept depression as a legitimate response to an awful life. Everyone prefers to treat the symptom as labeled rather than attend to the life. Compassion means just listening.

The Quest Story

When restitution can no longer be imagined, a life can be fashioned in which illness is neither “accepted,” a word that is too passive, nor is it “welcomed,” a word that romanticizes illness. Illness is lived as a quest: as a condition from which something can be learned (although not in a didactic sense), and this learning can be passed on to others. The line I hear and read most often from people who have had cancer is that they are certainly not glad they had it, but they are grateful for how it changed them and their lives.

Quest stories are being told when the teller claims new qualities of self and believes illness has been responsible for these changes. Quest stories are about illness leading to new insights. They are based on a claim that the ill person now sees *in* to a depth that illness has made visible. As I read the title of William Styron's (1990) memoir of suicidal depression, *Darkness Visible*, Styron's text not only makes the darkness of mental illness visible to readers; Styron also acknowledges that illness has made an aspect of his own life's darkness visible to him. Perhaps the key phrase in quest stories is some version of “I can now . . .” — although the expression of this phrase is usually muted. If, by the time the quest story can be told, illness is no longer chaos, if suffering now has some meaning and even value, the reality of chaos is still recognized and respected. The quest

6. Professional education emphasizes articulate answers, which is another reason why professionals have trouble hearing the wisdom of the ill. Professionals gain their status through their capacity to articulate what others cannot say; articulation becomes a standard of wisdom.

story fears being heard as a triumph over chaos; part of the lesson of deep illness is that victories are always provisional.

A subtle and therefore powerful example of the quest narrative is found in the life and work of Kay Toombs.⁷ Toombs suffers from a progressive, degenerative multiple sclerosis. At first she seems to repudiate the idea of illness as quest. She writes of giving a speech about her illness experience and being asked by audience members “to state explicitly those things that I find ‘good’ about my situation. Is it ‘enabling’ rather than ‘disabling?’ Has the experience caused me to ‘grow’ in certain ways?” To these questions Toombs answers, “Harsh though the reality may be, there is nothing intrinsically good about chronic, progressive multiple sclerosis. Nothing” (Toombs, 1995, pp. 19–20).

Yet Toombs also writes of how she found, without noticing exactly when, that she had begun “to reclaim my life” (p. 21). This reclaiming is not a sudden epiphany but a slow, gradual process. Toombs writes of what she has gained through illness — empathy for others’ suffering, friendships, and “a clearer view of what is really important in my life” — but she is equally clear that these “do not, however, make me glad that I have M. S.” (p. 20).

Gladness, at least about illness, has little place in the quest narratives; “reclaiming” figures largely. What Toombs does not state explicitly, but what her writing and speaking enact, is what illness has given her to teach. Summarizing someone else’s quest is a precarious matter, but I would presume to say that Toombs’ quest is to tell others about a world that illness has made her uniquely prepared to articulate. Illness has not given her a voice, but she has given a voice to illness. Another harsh truth is that I cannot imagine her writings having the force they have if she were not ill; the quality of witness could not be present. Toombs’ quest is to testify, and ultimately the quest narrative is testimony.⁸

The audience members who press Toombs to put a more positive spin on her experience of illness do not want her testimony. They want her reassurance that, if they become ill, they can find something “good” and “enabling” themselves. In my interpretation, they want not a quest story but a restitution story. They realize Toombs will not have her physical health restored, short of a miracle. Thus she embodies every healthy person’s fear of illness without restitution. But the audience members’ commitment to their own deep health can still be preserved by imagining a restitution in like measure. The audience wants to believe that what Toombs has lost in one aspect of her life, she has gained elsewhere. The quest story refuses this fantasy, even as it acknowledges what has

7. Toombs’ writing was not available to me when I wrote *The Wounded Storyteller* (1995). See also Toombs, 1992.

8. See Frank, 1995, Chapter 7, “Testimony.”

been gained. Toombs calls her response of “nothing intrinsically good” harsh, but I read her whole story as imbued with a wisdom that can only come from such harshness.

This wisdom is a matter of being exactly where one is, yet grateful for that. Reynolds Price (1994) expresses this gratitude at the end of his story of being rendered paraplegic by a malignant tumor inside his spine:

I write six days a week, long days that often run till bedtime; and the books are different from what came before in more ways than age. I sleep long nights with few hard dreams, and now I've outlived both my parents. Even my handwriting looks very little like the script of the man I was in June of '84. Cranky as it is, it's taller, more legible, with more air and stride. It comes down the arm of a grateful man. (p. 193)

I have heard Price say, in a radio interview, that at least once a day he wishes he could stand up for just a moment and stretch, but then he realizes his life will be spent in his wheelchair. The quest story is cranky but grateful. If Price is more explicit about his gratitude than Toombs, in part this may be because his disability is not deteriorating while hers is. Or perhaps Toombs is even more wary — Price is wary enough — of how much a healthy audience wants to dilute the harsh realities of the illness. She knows how easily the quest story can be read or heard as a restitution story, and she fears betraying (to use another harsh word) the suffering that illness is.

Quest stories express an unflinching view of the reality of illness. In the face of this reality, they look not to restitution but rather to what can be reclaimed of life: what can be learned, and how this lesson can be passed on to those who have not made their journey. Those who tell the quest story are ancient mariners, returned to tell a tale that others need to hear but may resist hearing. If the teller of the quest story is rarely pathologized in the way that the exemplar of the chaos narrative often is — even society honors the quest storyteller — people will rarely embrace quest stories. Why?

Listeners resist the quest narrative because they still need to believe in a restitution that the teller has had to work to give up; much of the quest concerns renunciation as a preface to reconstruction. Nancy Mairs (1996) writes of how living with advanced multiple sclerosis requires her to give up comparison to “The ‘her’ I never was and am not now and never will become,” lest she “make myself mad with self-loathing” (p. 47). No one living in even moderately good health, much less living in deep health, wants to imagine ceasing to be the person they enjoy being; it is far preferable to imagine that breakdowns can be fixed. Physicians and patients reinforce each other's commitment to restitution as the only speakable eventuality. But quest stories carry the unavoidable message that the restitution narrative will, one day, prove inadequate to what experience has in store for many of us. Because, as Kleinman notes in the quotation above,

physicians prefer to concentrate on cure and do not routinely find meaning in illness, they are not often disposed to listen to patients' attempts to reconstruct selves beyond restitution. I myself want a physician who concentrates on trying to cure me; but because that cure may be unavailable, I also want a person with whom I can share my story.

Thus listeners resist quest stories because of these stories' assertion, sometimes implicit and sometimes explicit, that the ill person has become what Price calls a new self. Deep illness requires giving up the old self, "the person you used to be" (Price, 1994, p. 182). Price's advice is to "find your way to be somebody else, the next viable you" (p. 183). He is clear that this quest will meet with the best intentioned resistance:

Your mate, your children, your friends at work — anyone who knew or loved you in your old life — will be hard at work in the fierce endeavor to revive your old self, the self they recall with love or respect. ... At the crucial juncture, when you turn toward the future, they'll likely have little help to offer; and it's no fault of theirs (they were trained like you, in inertia). (p. 183)

Price hints at the subversive quality of quest stories — a subversion that complements the chaos story's subversive display of how bottomless despair can be. Those living in "deep health" value objects, including themselves and those they love, in ways that are often far more instrumental and conditional than they are willing to acknowledge. Quest stories are about being forced to accept life unconditionally; or, in the stories of Price, Mairs, or Toombs, finding a grateful life in conditions that the previously healthy self would have considered unacceptable.

Not all ill people are oriented to these authors' level of introspection, nor do all have the physical capacities that allow such articulate tellings of their stories; rather, their stories have to be heard in how they live their lives. Physician and journalist Lonny Shavelson tells the story of Pierre Nadeau, a trapeze artist, dying of AIDS. Pierre's illness was marked by a series of "lines in the sand" that he is certain he would rather die than cross: getting AIDS, being plugged into oxygen, having chemotherapy and losing his hair, wearing diapers. Yet he does cross each of these lines (Shavelson, 1995, p. 55). As Shavelson describes him, Pierre does not tell many stories, yet Shavelson quotes a hospice nurse who speaks of his "amazing spiritual change" (p. 56). She seems to have heard, somewhere, a quest story.⁹ Perhaps this story is told most eloquently in Pierre's willingness to cross those lines he had said he would not cross.

9. Of course, we do not know what is interpreted as Pierre's "spiritual transformation." We know Pierre chose to continue to live, but was this choice motivated by a dread of dying,

The Pierre who draws his lines in the sand is closer to the values of healthy society than the Pierre who crosses those lines and in the process undergoes spiritual change. It seems a cliché to conclude that the skeleton underneath quest stories is the unconditional acceptance of life, yet perhaps the notion of unconditional acceptance has become a cliché because of its profound and unattainable value. Although quest stories are the narrative structure that is most eloquently told in prose, perhaps the most moving quest stories are those, like Pierre's, that are lived (see Frank, 1997a). In finding terms to live with illness — not grateful for illness, but grateful for a life that includes illness — those telling quest stories show the healthy how they too could be living.

Just Listening

The three types of stories I have described are not intended to classify tellers of particular stories. If they are diagnostic of anything, it is the culture and relationships within which people create their stories. But these types are not designed to diagnose. Rather they are listening devices: tools to help those who attend the ill to understand — not to decode — what they hear. For those who use these narrative types in their clinical work, three additional caveats are worth making explicit.

First, all three narratives *intertwine* in most stories told by any deeply ill person; few individual stories have only one skeleton. Often in a particular story, at a particular time, one narrative type is foreground and the others are background. Shifts in foreground and background map changes in illness experience. When listeners attend to which type of story seems more important than others, they can hear where the ill person is. Knowing *where* someone is, is important, but equally important is recognizing why they have to be where they are. I want to arouse clinicians' suspicions of assumptions that the ill person as teller ought to be in some other narrative space than where he or she is.

Second, although strong cultural and personal preferences exist for one type of story over another, all three types have their necessary places in all trajectories of illness experience. Each deserves to be *honored* in its time of telling; I will

or did Pierre find some value in life that he had not anticipated? The hospice worker's observation, as much as I would like to credit it, could be more a projection of her own need to find value in her work than it is an observation of Pierre's reality. But matters become more complex still: even if the quest story began as her projection, her story may still have become his reality and given him a resource to continue living. What counts is not who told which story first, but that, in a relationship with such intensity and duration of care, each person's story becomes the other's. Unfortunately, within contemporary medicine, hospice care is singular for its intensity and duration of personal care relationships.

discuss why and how in the following section. Because of this importance of honoring the immediate story being told, my narrative types are the opposite of a developmental theory that predicts ill people “moving through” stages of narrative, pathologizing the failure to keep moving. The quest story is not a goal toward which ill people ought to move, nor does the chaos story represent personal or social failure.

Third, listeners will certainly have distinct *preferences* for one type of story over another. I believe the proper initial use of the narrative preferences that we all have is to pose questions about oneself as a listener. If listeners find themselves wanting the ill person to move from one narrative type to another, that desire may say more about the culture (professional and social) of the listeners, their own anxieties and narrative commitments, than it says about the ill person.

My strong assumption is that *people tell the stories they need to tell in order to work through the situation in which they find themselves*. As long as a story continues to be told, the work of that situation continues to need doing. This assumption hardly obviates the desirability of change. It does suggest that, for the deeply ill, change cannot be hurried by external intervention; if anything, the processes that nurture change may become confused and set back. The corollary for clinical practice is that, when time is limited by “managed care” and other constraints, it is generally preferable to accept less change than to seek to hurry change by pressing a patient toward a new story. Better yet, rather than the pejorative implication of accepting less change, clinicians might think of change occurring after, perhaps long after, their work of listening has finished. In Tim Brookes’ story of his mother’s hospice care, he recounts a hospice physician telling him that often the value of their work is not apparent for twenty years (Brookes, 1997, p. 276). I believe the truth of that statement, and I find very moving the clinical conviction that allows this physician to conceptualize his work in that time span.

Change happens. Telling one’s own story can help move a person through a particularly difficult situation by providing some *critical distance*. When a story is well heard, it becomes something that teller and listener can talk about and reflect on. When experience becomes an object for what is now a mutual involvement, the teller gains some distance between what is being lived and what is being told. Only at this distance can actions — including interpretations — be perceived as possibly having alternatives, thus making change imaginable. This critical distance is the key to any “movement” that may occur.

Clinicians, especially those who trade most in the therapeutic value of clients reinterpreting their reality, may find it frustrating to remember how many restrictions illness imposes, and how difficult change is within these. Impositions are both external (by jobs, families, and “helping” systems themselves) and internal (originating in the body’s pains and disruptions, moving to the mind’s fears of these). These impositions may have to be told over and over before the ill person begins to sort out what can be reinterpreted, what can be endured, and perhaps what can be materially changed (quitting the job, getting improved

pain-medication). Out of retellings some critical distance *may* emerge, and *perhaps* some aspect of suffering can be assimilated to some “higher” scheme of meaning. But, as I will emphasize in my concluding comments on intervening in people’s stories, any higher assimilation of the meaning of present troubles can only be discovered by ill people themselves in their own storytelling.

More than Just Listening

Richard Zaner’s (1993) work presents the hospital ethicist as one who primarily listens to patients and helps them to sort out the ethical issues that are already inherent in their stories, if not yet reflected upon. He wonders whether, in doing this work, is he “any different from any good friend?” (p. 21). Clinicians reading this essay may have the same question. How is the role of “just listening” a *professional* role, making use of extensive training and — in a time of cost-cutting — justifying financial remuneration?

I have argued throughout that one listens to ill people’s stories not in order to fix them by doing something “therapeutic,” but rather to honor them. Again, people tell the stories they need to tell in order to work through the situation they are in. Efforts to change the person’s story, however well-intentioned, are so easily mistimed or misguided. Toombs, quoted above, exemplifies resistance to narrative intervention when she reacts against the questions posed by her audience; questions that presuppose what sort of narrative (“enabling”) she ought to be telling and coerce her to get it right.

The point of listening to Toombs is coming to realize that she *already* has it right. But does every ill person have it right in every story they tell? The paradoxical response is that every teller does have his or her own story right just as that story is: not fair, not necessarily accurate in a medical or sociological sense, but right as an expression of who and where they are. But — here’s the paradox — what’s right can still change, and that change may also be right and welcome. The resulting clinical problem could be called the nonelicitation of change. How to do this nonelicitation returns us to Zaner’s question: What does the clinician do that the good friend may not be able to do?

My first response to this question is to want to rescue clinicians, as professional listeners, from imagining their role as dichotomously opposed to that of the friend. Instead, I understand the clinician as one who may enact certain “friendship” roles using different resources. A common experience for the deeply ill is to have many of their former friends disappear. In the world of deep illness, friends die or become physically unable to visit with greater than average frequency. Healthy friends defect from the tensions and demands of being with the ill. Friends who do not disappear outright may be uncomfortable with talk about deep illness: their own fears of illness admit only restitution stories. Thus, friends may be the least willing to sustain the ill person through struggles over decisions that admit no “good” resolution: for example, whether to opt for

debilitating therapies that offer a small chance of remission, or whether to choose palliative care with a better quality of life in the short term but no chance of remission.¹⁰ Friends may be too threatened by the suffering involved in either “option” to be useful in talking through this “choice.” The first requirement for professionals is to have control of their own sense of threat. This control should not preclude empathic sharing of the sorrow involved in having to make such a choice, but such empathy cannot be weighed down with the clinician’s own fears and regrets.¹¹

Long-standing, personal friends may also be poor listeners to stories of personal change because, as Price predicts in the quotation above, they want to steer the ill person back to being the self who was. Friends are often least willing to watch an ill person’s painful groping toward the self who may yet be; they cannot hear the stories in which that new self assumes an increasingly real identity. The clinician has the advantage of having no stake in the ill person continuing to be who she or he was before illness. The clinician should neither be threatened by changes that illness can precipitate, nor be overly invested in seeing the ill person change. Anything beyond just listening is not directed at fixing the story, but rather is about *nurturing* it.

Let me be honest about having my own preferences and ideals. When I encounter ill people, I have to question whether I am nurturing *their* story or fostering my own preference. Perhaps I have too many exemplars of illness in my head — too many quest stories — and I have to work to separate what I might hope for the person who is with me from that person’s own trajectory of meanings of illness. Most therapies agree that people must *discover for themselves* that change is possible; therapies begin to differ over how to instigate or facilitate that discovery, and how fixed an idea the therapist should have of what change ought to occur. In both respects, the instigation of change and the content of change, therapeutic work that attends to people’s stories is far at the nondirective end of the spectrum. As I suggested earlier, stories are not told as “clinical material” in order to keep a “therapeutic process” moving.

Stories are told to cultivate relationships. In a relationship, we come to know ourselves as we are known, and we may change with that knowledge. For either person in a relationship, change is something that is allowed to happen. If I as a listener welcome certain stories more than others because they fit my ideal of self-knowledge, I limit my relationship with the person telling the story; I render his or her story instrumental to some “higher” goal that is mine, not necessarily

10. I draw this example specifically from Timothy Quill’s famous “Diane” case (Quill, 1993), although the scenario is a common one.

11. On empathy in medical relationships, see Spiro, Curnen, Peschel, and St. James, 1993, especially the papers by Rita Charon, Jodi Halpern, and Stanley Joel Reiser.

the other's. Relationships, and friendships, seem to require that the story be an end in itself, although stories do change, and friends change with them.

Personal discoveries of meaning take place at unpredictable moments when — tautologically — people are prepared to make that discovery. I can advance the theoretical propositions that change occurs when the restitution narrative is no longer viable and when the chaos narrative is no longer necessary, yet these propositions have the unhappy effect of setting up the quest story as the kind of narrative *telos* that I have been working to avoid. In practice, no one can say when these moments of change will occur for any ill person, only that they do happen as both ill people themselves and their caregivers attest. How then can change be nurtured, without being directed?

My first suggestion for nurturing change is to hold the utterly sincere belief that the story you are hearing *needs no change*. The ill person's whole life has brought him or her to this story, and deep illness is no time for anyone to repudiate how that life was lived. The ill person himself probably has sufficient regrets and self-reproaches. The best opening to change may be the recognition that the story the person is now telling is a perfectly adequate representation of his or her experience, *which it is*.

Again, this message has to be entirely sincere. Sincerity depends on the listener's willingness to accept both regret and suffering as part of life, both inevitable *and* remediable. I believe that clinical work becomes uncertain at best, and evasive at worst, when clinicians lack their own beliefs — philosophical or spiritual — about suffering. My own belief is that humans do have to suffer; call it our existential destiny. But there are better ways to suffer; call those ways grace. Whatever the clinician's own beliefs, as a listener, she or he should assume an attitude diametrically opposite to that of Toombs' questioners, who want to see only the remediable side of suffering.¹² The clinical attitude I recommend may reject the chaos narrative's supposition that suffering is *only* inevitable, but it honors chaos as a necessary part of life.

To work with the deeply ill, I believe a clinician must be able to honor suffering. Honoring suffering shapes the spirit of helping. The helper who honors suffering can accept the "dark night of the soul" but also offers the immediate, practical help others need. Part of this help is recognizing that people are telling the story they need to tell, for a while, before they can move on.

A second aspect of nurturing is to help the ill person *hear exactly what story* she or he is telling. Everyone is a storyteller, but few of us are sufficiently reflective

12. Even worse is the attitude of Job's friends, who want to believe that suffering must be deserved. Believing that suffering is an inevitable part of human life seems to free us from believing that any individual's suffering is deserved, while allowing us to see how individuals continue to make choices that affect how they suffer.

about what stories we tell, in our lives and words. Only through reflection can storytelling, and life, become truly ethical. To hear the story being told, my three types may be useful. Does the hope of restitution leave open other possibilities? Can the chaos story be told until the teller can feel its claustrophobia as part of the tale, outside of how life is being lived? And how is the present story turning illness into a quest? Any actual story should include elements of *all three* narratives, because each of these questions deserves reflection. Sorting out the three narrative skeletons in any actual story does not direct the story away from one story and toward another. The point is to show the ill person that the story *already* contains different, immanent narrative directions: a direction that is now mostly in the background could become foreground.

The third aspect of nurturing is that listening carries the message, which is not self-evident for the deeply ill, that they are living *a story that is theirs to tell*. Everyone else seems to have a story *about* the ill person, but few people have an interest in that person's own story. Very soon the ill person begins to doubt the interest of his own perceptions. Nurturing begins and ends in the message that no one knows their stories better than the ill themselves, that their stories matter not just for themselves but for others, and that their stories can be told, and lived, differently. Noting a change between what is said one day and the next, without interpreting that change, affirms to the ill person that it's *his or her* story, to tell as he or she will.

The situation of the ill changes rapidly: the body's condition changes; the conditions of treatment and care change; professionals move to new jobs; friends and family members get sick themselves, or defect, or reengage with the ill in strengthened relationships. These changes require new stories, and every type of story has its day.

But what if the ill person's story seems to be overstaying its day? It is seductively easy to observe that ill people get stuck in one narrative when they would do better to have greater narrative flexibility. Flexibility is a popular value.¹³ Less popular is the idea that people may need time and repetition to work through all the possibilities of a narrative they have relied on throughout their lives. Before flexibility comes the importance of learning what one's own inflexible narrative has meant for all these years: how this narrative was shaped by one's circumstances even as it shaped those circumstances, how it was once the person's best possible response to what life offered, and how much the person owes to this narrative. Words like "stuck" fail to honor the stories that have been a person's life. If some stories now seem to limit their tellers, let us not forget that the ability to tell these stories may have once been hard-won.

13. For a brilliant analysis of the increasing status of flexibility as a cultural value, see Martin, 1994.

Many stories do need to change. Letting people tell their story repeatedly, gently noting changes in that story, can help. Most significant to the process of change, the person who is so attended is no longer alone.

Anatole Broyard (1992), when he was dying of prostate cancer, wrote that his “first instinct was to try to bring [cancer] under control by turning it into a narrative.” He describes stories as “antibodies against illness and pain” (p. 20). Broyard’s ideal relationship to a physician was based in narrative: “I want to be a good story for him, to give him some of my art in exchange for his” (p. 45).

Fortunately, most ill people have some art to exchange for their care. The greatest clinical gift to the ill is to appreciate them as the “good stories” they are. In these stories there is nothing to fix, only a great deal to listen to.

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