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Stories of Illness: Authorship in Medicine

J. Wesley Boyd

KAY REDFIELD JAMISON. *An Unquiet Mind: A Memoir of Moods and Madness* (Knopf, 1995). 224 pp.

SUZANNA KAYSEN. *Girl, Interrupted*. (Turtle Bay Books, 1993). 169 pp.

JOHN MACK. *Abduction: Human Encounters with Aliens*, rev. ed. (Ballantine, 1995). 464 pp.

CHRISTINA MIDDLEBROOK. *Seeing the Crab: A Memoir of Dying*. (Basic Books, 1996). 212 pp.

OLIVER SACKS. *An Anthropologist on Mars: Seven Paradoxical Tales*. (Knopf, 1995). 328 pp.

LAUREN SLATER. *Welcome to My Country*. (Random House, 1996). 199 pp.

WILLIAM STYRON. *Darkness Visible: A Memoir of Madness*. (Random House, 1990). 84 pp.

Being ill is a common but nonetheless special kind of experience. It can separate us from the usual world that we inhabit and cause us to take time away from our daily activities. Perhaps force us to leave loved ones. Possibly even bring us near death. Being ill can, therefore, give us the space and distance to see our normal lives with fresh eyes and provide us with an opportunity for growth.

Because of potential significance, it is important to clarify the ways that we talk and think about illness. Largely, I would argue, both doctors and patients talk

about illness in narrative terms. Eric Cassell (1985) writes that diseases themselves are stories:

A disease is not a thing, it is a process. A process is characterized by change over time. Events are steps in a process and can be identified in space and time. Just as in a story, events occur over time, so they do in a disease. In other words, not only is the history of an illness a story of events happening to characters through time, but a disease is a story, too. (p. 17)

So, diseases are stories. But also much of what happens around diseases also involves stories. Our patients offer us stories of their illnesses, we create versions of these stories in our notes, we tell stories to our colleagues about our work, and we construct stories about the likely outcome of the interventions we consider. Medicine in general, therefore, and psychiatry in particular, is heavily dependent on stories. Some might even say these are story-bound enterprises.

In this article I review several accounts of illness, most told by patients and/or sufferers of illness but some others told by their caregivers. I have separated my analyses of accounts of illness into first-person accounts and third-person accounts (with one account that bridges the gap between first and third person). To some extent this mode of organization is arbitrary, because there are certainly other ways that I might have categorized and/or segregated the works which follow. For example, I might have separated the

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works by what Anne Hunsaker Hawkins (1993, p. 165) calls their organizing myths and metaphors. Are we dealing with a story of battle? A flight into health? A story of rebirth? A journey?

There are other options for sorting these works too. I might have separated them by the nature of the illness they depict, or by whether or not they are told by health care practitioners, or by how "fictionalized" they are.

Several preliminary remarks are in order. In what follows I clearly privilege first-person accounts over others. First-person accounts may not, ultimately, be more "true" in the sense of adhering more closely to what "really" happened, but they are somehow closer to their source than accounts from without, and so perhaps are more honest.

Furthermore, I confess to being skeptical toward professionalism and the authority it supposedly confers. Although our various training endeavors hopefully provide us with lenses and amplifiers for hearing and seeing better, they do not necessarily do so. And because our training can be so powerful in *some* arenas, we are not always able (or encouraged) to see the limitations in others. The people who come into our offices are quite often those who have not been treated well by our culture, and we must be careful not to further deprive them of a voice because of our expertise, because we feel we know better than them what has happened or how they should feel. To do so would be to intensify the power discrepancy that usually exists between caregivers and patients.

Stories of medicine often are attempts to claim authority and power over illness, whether or not the teller is a patient or a caregiver. When patients write about their experiences of illness, they often seem to want to reclaim authority over themselves that (they may feel) was denied them by the machinations of medicine. If we can hear their stories with fresh ears, without the preconceptions and assumptions that can make genuine hearing impossible, perhaps we will be better able to hear our own patients when they come

into our office, bearing a story and hoping for help.

FIRST-PERSON ACCOUNTS

In this section I examine Christina Middlebrook's (1996) *Seeing the Crab: A Memoir of Dying*, William Styron's (1990) *Darkness Visible: A Memoir of Madness*, Kay Redfield Jamison's (1995) *An Unquiet Mind: A Memoir of Moods and Madness*, and Susanna Kaysen's (1993) *Girl, Interrupted*. Middlebrook and Jamison are both primarily mental health practitioners—Middlebrook is a nonmedical Jungian analyst, and Jamison is a psychologist on faculty at Johns Hopkins—and the other authors are both primarily writers. Despite these differences, each of these works advocates for humane, respectful patient-centered treatment.

Middlebrook's (1996) *Seeing the Crab* is unique in this group in that it principally details her struggles with a physical illness—cancer—instead of psychological illness and its treatment. Her book begins after she has been diagnosed with metastatic breast cancer. Her title is a metaphor for the fact that cancer is crablike in its presentation. Middlebrook, who had long been a crab hunter and took pleasure in teaching her children the art of crabbing, writes:

There is a moment when the crab appears. . . . You have to go for it right then, without hesitation. Just grab. . . . It is a moment of faith. Faith that the hold you've taken will keep the wildly swinging claws out of reach. Trust that the claws cannot reach backwards to your fingers. (p. 14)

Like a crab, cancer is furtive. It moves sideways; it is "a shifty beast" (p. 14). Like the grab required to tame a crab, cancer thrusts us into a partly unknown, often terrifying world.

Middlebrook's account is hauntingly stark and in some ways unsympathetic. She rejects New Age displacements, sensibilities, and pronouncements about her cancer. She does not attach any moral significance to her cancer—it is not a judg-

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ment on the quality of the life she has led—and she cannot cure herself by positive, healthy thinking. Middlebrook continually highlights the awesome destructive randomness of her cancer.

Contrary to all my training, training that promised that the more prepared I am the more apt I will be to survive, I learn that training is for nothing. Bombardment. Incoming. Forces of nature. Those are what may kill me. Nemesis is large, impersonal, random, unfocused. No help my marksmanship, my physical fitness. No help my positive attitude, my willpower, my fat-free diet. (p. 85)

Illness can expose us as fundamentally impotent at times against the brute force of illness, in much the same way that (large-scale) natural disasters can expose our helplessness against nature in general.

There is a stark dignity in *Seeing the Crab*. In a typical account, Middlebrook writes of not having enough life in her to activate the automatic sensor at a sink in a rest room at O'Hare Airport in Chicago.

I stood in front of the eye and nothing happened. The great stillness I was living did not carry enough molecular energy to catch the eye's attention. I had to ask a livelier woman to come and stand before my sink to make the water run. . . . Needing to ask the woman at the next sink to stand in for me, needing to borrow from her vitality simply to wash my hands, made manifest the fact that I had been separated from life as others live it. (p. 35)

In another vignette Middlebrook tells of the procedure of harvesting her own blood cells in anticipation of a future transplant.

The force of the pheresis procedure is such that no ordinary little needle, no ordinary catheter, can be used. . . . We need a vas-cath. The doctor holds it up for me to see. It looks like a #5 knitting needle, just as thick and just as long. He tells me exactly how he is going to tunnel it into my subclavian vein. He explains why he cannot use an anesthetic during his procedure. I know beyond all knowing that this time I will have to face it straight on.

I lie in the white bed seeing the children's faces, each framed in a time years past. Each beseeches me for one more scheme, one more

way to avoid a task that makes no sense. This time I have nothing to offer. . . .

An ache as deep as the breaking of a bone snakes through my chest and down my right arm, withering my will. Oh, to cheat right now. The vas-cath lies buried a knitting needle's length into my chest. (pp. 52-3)

Middlebrook is not looking for sympathy. She is not offering hope. She is not advising us on how to think correctly and positively about illness in order to defeat it or conquer it. Instead, she is writing to encourage us to face death as an integral part of life, even if we are not terminally ill. This understanding yields a more realistic sense of ourselves as mortal creatures. As Martin Heidegger (1962) told us in *Being and Time*, we are Beings-unto-Death, always bound by the horizon of our own death, and we cannot understand ourselves apart from our relationship to our own death. Seeing ourselves in this way also has the added benefit of not rendering the terminally ill as radically separate (or different) from the rest of us. Thus, *Seeing the Crab* challenges us to not extrude death from life, to not see death as "wholly other."

An illness like cancer lacks all regard for our hopes and plans for ourselves, for the stories we wish to write about ourselves.

I have lost any thought of returning to my old life, watching my children enjoy graduations and find work and marry and have children. I do not think of my work, and its attendant conferences and meetings and committees. There isn't any question anymore about my retirement. . . . I do not expect to know my grandchildren. I do not expect to grow old. (Middlebrook 1996, p. 84)

By writing *Seeing the Crab*, Middlebrook reclaims some of the voice that cancer denies her. Although ultimately she does not "triumph" over breast cancer in the usual sense—that is, she does not go into remission by book's end—Middlebrook does triumph in the sense of finding a voice for herself in her illness, even in the face of an illness which works as hard as it can to take that voice from her. Middlebrook evokes sympathy in us (although

she does not ask for it), informs us, and expands our sense of what it is to be alive.

Middlebrook progressively reveals more of herself in her work, progressing from the less personal and embarrassing aspects of her illness to the most personal. In an excruciatingly honest late chapter, she writes about the effects of her cancer and treatment on "sex, shit, menopause, and money" (p. 170). She even writes about how she took some of the money contributed to the Christina Middlebrook Bone Marrow Fund and bought a pickup truck (p. 188). Middlebrook is no pristine warrior. She is willing to risk our wrath, and because of this she is profoundly human, and her story all the more compelling.

In *Darkness Visible*, William Styron (1990) conveys the insidious nature of a depression that struck him while he was in Paris to receive the Prix Mondial Cino del Duca, a major literary award, a time when, were there justice to such things, Styron should have been on top of the world. Styron's depression thus seems as random Middlebrook's cancer.

By writing about depression, Styron is trying to convey something which, due to its nature (largely) defies words and militates against communality.

That the word "indescribable" should present itself is not fortuitous, since it has to be emphasized that if the pain were readily describable most of the countless sufferers from this ancient affliction would have been able to confidently depict for their friends and loved one (even to physicians) some of the actual dimensions of their torment, and perhaps elicit a comprehension that has been generally lacking; such incomprehension has usually been due not to a failure of sympathy but to the basic inability of healthy people to imagine a form of torment so alien to everyday experience. For myself, the pain is most closely connected to drowning or suffering—but even these images are off the mark. (pp. 16–17)

This ineffability is perhaps a facet of all illness, but it is even more so in mental illness because the mind is directly affected.

In spite of the difficulties facing him, Styron does a remarkable job communi-

cating his experience of profound depression, and the loneliness and anergia that accompany it.

I felt an immense and aching solitude. I could no longer concentrate during those afternoon hours, which for years had been my working time, and the act of writing itself, becoming more and more difficult and exhausting, stalled, then finally ceased. (p. 46)

Styron also ably conveys the anxiety that overwhelmed him in addition to his depression:

There were also dreadful, pouncing seizures of anxiety. One bright day . . . I heard a flock of Canada geese honking high above trees ablaze with foliage; ordinarily a sight and sound that would have exhilarated me, the flight of birds caused me to stop, riveted with fear, and I stood stranded there, helpless, shivering, aware for the first time that I had been stricken by no mere pangs of withdrawal but by a serious illness whose name and actuality I was able finally to acknowledge. (p. 46)

Perhaps part of the reason depression is so hard to talk about is that its causes, its origins, are often obscure. Understanding requires knowing something about origins, but Styron could not discover a "cause":

I shall never learn what "caused" my depression, as no one will ever learn about their own. To be able to do so will likely forever prove to be an impossibility, so complex are the intermingled factors of abnormal chemistry, behavior and genetics. Plainly, multiple components are involved—perhaps three or four, most probably more, in fathomless permutations. That is why the greatest fallacy about suicide lies in the belief that there is a single immediate answer—or perhaps combined answers—as to why the deed was done. (p. 39)

Without a cause for his depression, Styron's story is not as complete as it might be. He cannot tie together all of its loose ends. In his honesty about not fully understanding what happened to him, Styron relinquishes (some of his) authorial control over his story. Perhaps there is always tension between being honest about one's material and narrating a coherent, "tidy" story.

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Despite the gaps in his understanding about the causes of his depression Styron is exceedingly clear about his feelings toward his psychiatrist, Dr. Gold (a pseudonym) – Yale trained and highly qualified.

We began to chat twice weekly, but there was little I could tell him except to try, vainly, to describe my desolation. Nor could he say much of value to me. His platitudes were not Christian but, almost as ineffective, dicta drawn straight from the pages of *The Diagnostic and Statistical Manual of the American Psychiatric Association* . . . and the solace he offered me was an antidepressant medication called Ludiomil. (pp. 53–4)

We can assume that Styron's feelings about Dr. Gold are colored by his depression, so how much of his account should we trust? We cannot know with certainty what Gold said to Styron – there is no authority to consult to verify Styron's account.

Regardless, it does not seem like a stretch of our imagination to think that, when faced with the extent of Styron's depression and his lack of response to treatment, Dr. Gold might have offered hope of some kind or another. When we are confronted in our work with the kind of despair that Styron relates in *Darkness Visible*, it is hard not to try to comfort our patients and to offer them hope. It is difficult not to simply affirm the pain and suffering (while at times offering statistics or prescribing medications). But that is what we must do so that we do not further isolate (by retreating from) the person before us. Anytime we think of some future and turn our attention away from the present, we are turning away from the individual before us and retreating into abstractions. If we cannot stand the pain of the present, how can we expect our patients to?

Perhaps there is something about clinical settings which militates against understanding others. Perhaps our degrees and titles hinder genuine encounters with others, because they implicitly encourage us to rethink and rework what we are hearing, to turn away from what is before us. Perhaps our medical/psychiatric language subtly but systematically alters

what and how we hear those who come into our offices. If so, then perhaps Styron's book is a product of all that we have not heard in our meetings with patients.

Kay Redfield Jamison (1995), a psychologist on tenured faculty at Johns Hopkins and an expert on manic depression, goes public with her own manic depression in *An Unquiet Mind*, opening her world to us, with all of its tragic-wonderful highs and death defying lows. *An Unquiet Mind* is a brave work. Jamison is brave for coming out to a profession that, unfortunately, may not be as understanding about such illnesses as it ought to be.

Although Jamison is an expert in manic depression, we could probably surmise that *An Unquiet Mind* represents Jamison's efforts to come to (further?) terms with her own struggles with manic depression.

In *An Unquiet Mind* Jamison recounts even her most painful, tragic, and poignant moments with deftness and humor. She also blends her extensive knowledge about manic depression with her own life narrative, a rich educative experience for her readers.

She speaks of how long she resisted acknowledging her illness and, later, of how difficult it was for her to accept her (life-long) need for lithium. It is as if Jamison did not want to put words on who she was, because the words would somehow make her condition more real, more undeniable. Doing so would also call to her attention all that she had lost.

I remembered exactly, and with visceral force, what I had felt reading it not long after I had started taking lithium: I missed my home, my mind, my life of books and "friendly things," my world where most things were in their place, and where nothing awful could come in to wreck havoc. Now I had no choice but to live in the broken world that my mind had forced upon me. I longed for the days that I had known before madness and medication had insinuated their way into every aspect of my existence. (pp. 96–7)

Jamison did not want – or perhaps was not ready – to narrate a story about herself that endorsed the fact that she suf-

ferred from manic depression and needed to take lithium forever. Her psychiatrist, among other people, helped her author a more helpful and accurate story about herself. She writes that her psychiatrist "never wavered in his conviction that I needed to take lithium. He refused, thank God, to get drawn into my convoluted and impassioned web of reasoning about why I should try, just one more time, to survive without taking medication" (p. 102). Jamison's psychiatrist helped her reconcile the story she told about herself with what she was experiencing. Any of us can delude ourselves to some extent, and input from others—particularly astute observers like Jamison's psychiatrist—can push us toward greater self-understanding.

Jamison is profoundly aware of the debt she owes her psychiatrist.

The debt I owe my psychiatrist is beyond description. I remember sitting in his office a hundred times during those grim months and each time thinking, What on earth can he say that will make me feel better or keep me alive? Well, there was never anything he could say, that's the funny thing. It was all the stupid, desperately optimistic, condescending things that he didn't say that kept me alive; all the compassion and warmth I felt from him that could not have been said; all the intelligence, competence, and time he put into it; and his granite belief that mine was a life worth living. He was terribly direct, which was terribly important, and he was willing to admit the limits of his understanding and treatments and when he was wrong. (p. 118)

Jamison's description illustrates the importance of merely being present for our patients and not trying to soothe them with platitudes or promises of a better future. Jamison's psychiatrist is far removed from Styron's Dr. Gold.

Oddly, despite the horrors she portrays in *An Unquiet Mind*, Jamison does not seem to have a tragic sense of life. She seems to have faith in fairness, in her family and upbringing, and a sense that everything will work out well.

Consider her thoughts on tenure, for ex-

ample. Although Jamison writes that "tenure is the closest thing to a blood sport that first-class universities can offer" (p. 124), she defends it, writing, "Fortunately, the tenure process has many checks and balances built into it, and, at least in the two universities that I know best . . . the system seems to me to be a remarkably fair one" (p. 134).

Or consider Jamison's account of her posttenure celebrations:

I celebrated for weeks. One of my best friends had a lovely dinner party for about thirty people, on a perfect California night; the terraces in her gardens were filled with flowers and candles; it could not have been more beautiful. My family provided the champagne, and I had a wonderful time. (p. 134)

Jamison is so comfortable that the wanton destruction of manic depression becomes little more than an unruly guest at a ball.

It is hard for me to understand how Jamison can retain a belief that *any* aspect of the world is fair or feel so comfortable with parties, given the gross unfairness of an illness like manic depression, much less something so notoriously problematic as tenure. If her illness has done anything for her, shouldn't it have instilled in her a tragic sense of life, one in which hard work is not always rewarded fairly? Tenure may appear to be fair if one is blessed with intelligent parents and a dissertation advisor with clout, but it may not appear so to one who suffered from anoxia at birth, alcoholic parents, stray bullets flying through one's neighborhood, or systematic prejudice; to someone who has little chance of graduating from college much less ever joining the faculty.

In spite of these hesitations, *An Unquiet Mind* nonetheless provides a powerful look inside the life of a gifted thinker who suffers from manic-depression. It is and is filled with wonderful observations and humane insights, and it deserves the wide reading it has had.

Susanna Kaysen's (1993) *Girl, Interrupted* offers an account of Kaysen's time

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as a patient in McLean Hospital in Belmont, Massachusetts. She intersperses her own recollections with excerpts from the McLean documents and records pertaining to her. These McLean records, along with the *DSM-III-R* (which she addresses in one chapter), become the foil for her own narrative.

After opening *Girl, Interrupted* with a copy of the first page of her McLean case record folder (which recorded identifying data such as name, birth date, address, diagnosis, etc.), Kaysen begins her narrative (if we are even justified in speaking about Kaysen's narrative apart from the total narrative of *Girl, Interrupted*) by writing that the world of the mentally ill is a parallel universe:

And it is easy to slip into a parallel universe. There are so many of them: worlds of the insane, the criminal, the crippled, the dying, perhaps of the dead as well. These worlds exist alongside this world and resemble it, but are not in it. (p. 5)

Kaysen juxtaposes narratives from two universes.

A case in point: Kaysen includes a copy of the notes made by the psychiatrist who evaluated her and sent her to McLean for admission.

I referred [Ms. Kaysen] to McLean Hospital for admission. My decision was based on:

1. The chaotic unplanned life of the patient at present with progressive decompensation and reversal of sleep cycle.
2. Severe depression and hopelessness and suicidal ideas.
3. History of suicide attempts.
4. No therapy and no plan at present. Immersion in fantasy, progressive withdrawal and isolation. (p. 13)

Kaysen disagrees with this psychiatrist's characterization of her, including her diagnosis. She writes, "My chronic feelings of emptiness and boredom came from the fact that I was living a life based on my

incapacities, which were numerous" (p. 154). She goes on to say, however:

My self-image was not unstable. I saw myself, quite correctly, as unfit for the educational and social systems. But my parents and teachers did not share my self-image. Their image of me was unstable, since it was out of kilter with reality and based on their needs and wishes. They did not put much value on my capacities, which were admittedly few, but genuine. (p. 155)

Kaysen disputes the story that was told about her by both her psychiatrist and McLean, and he argues for her own version of events. She cares about what we think, about which story we believe, long after the fact and even though we cannot "take back" what happened to her. This is testimony to the fact that stories are important in and of themselves and powerful on many levels – not just because a particular story can cause us to be committed to psychiatric care or earn us a shot of Haldol in the bum.

Kaysen even disputes her psychiatrist's contention that he interviewed her for 3 hours before he sent her to McLean. In a chapter entitled "Do You Believe Him or Me?" Kaysen also writes: "The doctor says he interviewed me for three hours. I say it was twenty minutes. Twenty minutes between my walking in the door and his deciding to send me to McLean. . . . We can't both be right. Does it matter which of us is right? It matters to me" (p. 71). She then carefully reconstructs the morning of her admission and ends the short chapter with, "There we are, between nine and nine-thirty. I won't quibble over ten minutes. Now you believe me" (p. 72).

Which of the narratives of her illness we should accept as most accurate? Most of us would, I surmise, be inclined to accept Kaysen's story, though perhaps with minor qualifications. She is, after all, the "author" of the book and obviously well enough now to reflect and to write coherently and reasonably. Also, there is no voice in the present to compete with Kaysen's, so her voice is unopposed. And finally, practitioners are generally more

willing to give credence to patient accounts now than they were 30 years ago.

Should we even ask what Kaysen's psychiatrist would say in his defense? Maybe he had heard so much about Kaysen's self-destructive behaviors that the decision to commit her was a *fait accompli* before she even arrived at his office, and her postinterview story was already written for her, without her knowledge or consent. (But again, we need to ask who was telling him these stories and what their motivations were.) Maybe he wrote 3 hours because that was the total amount of time he spent on her, if not *with* her.

Is our reaction to *Girl, Interrupted* changed by the fact that Kaysen's diagnosis is borderline personality disorder instead of a more "biological" illness? Kaysen thinks so.

I guess I've had my share of unreliaables. More than my share? How many would constitute more than my share? Fewer than for somebody else—somebody who'd never been called a borderline personality? There's the nub of my problem here. If my diagnosis had been bipolar illness, for instance, the reaction to me and to this story would be slightly different. That's a chemical problem, you'd say to yourself, manic-depression, Lithium, all that. I would be blameless, somehow. (p. 151)

If our stories are (largely) out of our control, then we become victims, players in a story written from without.

In sum, then, in *Girl, Interrupted* Kaysen reclaims her own story for herself and takes it out of the hands of the psychiatric/medical community. Not surprising, she feels compelled to argue for why her account ought to be believed and not those of her various caregivers. Hers is a small voice straining to be heard over a very large, powerful adversary. Kaysen's case reminds us to listen for voices that may appear to be small compared to those of psychiatry, and organized medicine more generally.

Girl, Interrupted provides a good lead in to the next section of this essay in which I take up a discussion of two third person accounts of illness. Unlike Kaysen's work, which is both first and third

person, subjective and objective, we will turn to works that take up their material strictly from without, describing the experience of others.

THIRD-PERSON ACCOUNTS

I now focus my attention on two third-person accounts of human experience and illness. One of these is Oliver Sacks's (1995) recent work, *An Anthropologist on Mars*, and the other is John Mack's (1995) *Abduction: Human Encounters with Aliens*.

In *An Anthropologist on Mars*, Sacks tells seven stories of people who are unique in some way. Some, such as the painter who lost all perception of color after a car accident, have suffered traumas. Others, such as the surgeon with Tourette's syndrome or the autistic artist, were born with their abnormalities. In his usual fashion, Sacks humanizes his subjects by focusing on the positive transformations that these traumas and afflictions have brought about.

Defects, disorders, diseases . . . can play a paradoxical role, by bringing out latent powers, developments, evolutions, forms of life, that might never been seen, or even be imaginable, in their absence. . . . [There is a] paradox of disease . . . [a] "creative" potential. (p. xvi)

Sacks later speaks of transforming the minus of the handicap into the plus of compensation (p. xvii) Sacks's subjects come to incorporate their respective problems (illnesses or accidents or setbacks or, in the parlance of the day, "challenges") into their sense of themselves, so much so that they would feel incomplete without them. In thinking as he does, Sacks forces us to question our assumptions about normality and about what it means to have an illness or handicap. Indeed, can we even label something an "illness" or a "handicap" if, after an initial period of adjustment, the person comes to feel whole and complete and content as is?

Consider the following example from *An Anthropologist on Mars*. A few years after his accident, a physician suggested

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that the colorblind painter try to regain his color vision.

In the first months after his injury, he said, he would have embraced such a suggestion, done everything possible to be "cured." But now that he conceived the world in different terms, and again found it coherent and complete, he thought the suggestion unintelligible, and repugnant. Now that color had lost its former associations, its sense, he could no longer imagine what its restoration would be like. Its reintroduction would be grossly confusing, he thought, might force a welter of irrelevant sensations upon him, and disrupt the now-reestablished visual order of his world. He had been for a while in a sort of limbo; now he had settled—neurologically and psychologically—for the world of achromatopia. (p. 39)

The colorblind painter's sense of what was normal for him had changed in the years since his accident. And with it, his entire sense of himself, his personal narrative, had changed. In a sense, therefore, this (and the other accounts in Sacks's work) is a story of redemption because the colorblind painter took events that were authored from without, beyond his control, and incorporated them into a new story, a new understanding, and made them his own. Sacks's work wonderfully illustrates the ways in which a traumatic, unwilling narrative disruption can ultimately be transformative.

What is Sacks's role in this transformation from disaster to opportunity? After all, Sacks clearly spends a lot of time with his subjects, and isn't it likely that they, most of whom probably are well acquainted with Sacks's work, feel compelled to tell Sacks what he wants to hear? And besides, Sacks's subjects are not a random sample in the first place. Sacks probably only hears stories from people who have made the transformations he describes—and perhaps even craves.

This same issue, with farther reaching implications, has been raised regarding John Mack's (1995) work with people who say they have been abducted by aliens. In his work *Abduction*, Mack presents the accounts of 13 such people. If we believe them, none of these abductees desired the

experiences they have had, and generally their abduction experiences represent a traumatic disruption in their life. Like Sacks's subjects, ultimately many of these abductees incorporate their traumas into their sense of themselves, into the narrative that (Mack tells us that) they tell about themselves.

The accounts in *Abduction* challenge the very foundations of our understanding of ourselves and of our place in the universe. Mack is well aware of this fact:

This book is not simply about UFOs or even alien abduction experiences. It is about how this phenomenon, both traumatic and transformative, can expand our sense of ourselves and our understanding of reality, and awaken our muted potential as explorers of a universe rich in mystery, meaning, and intelligence. (p. xiii)

Mack later notes that the entire phenomenon deeply violates "our scientific worldview and the implied control of our living environment that accompanies it" (p. 434). From his starting point of the narratives of individuals, then, Mack wants us to rethink the narrative of our whole culture.

Although the stories in *Abduction* are fascinating—if troublesome—and should be read, I find myself even more interested in the firestorm around them. Because Mack takes these accounts seriously, he has found himself under attack, both from the general scientific community as well as the academic community of Harvard, where he is a professor of psychiatry. For over a year Mack was investigated by a handpicked committee (by the dean of Harvard Medical School) of his Harvard colleagues. Whatever else Mack's fight was about, it was about authorship: Who, in the end, should be allowed to narrate stories of abduction and have final authority over them? (Perhaps the more academic among us, the experts, feel better able to decide what is true or not about such accounts. Perhaps these experts have more to lose if Mack's accounts are true.)

In the revised edition of *Abduction*, Mack addresses his critics. He challenges those who contend that memories of alien

abductions are nothing more than disguised memories of more terrestrial forms of abuse.

There is, as yet, no recorded abduction experience that proved, upon investigation, to be a reflection of some other trauma or experience, despite a great deal of effort on the part of investigators to find some other source for these experiences. . . . It seems clear to me at this time that we are not dealing with "false" or confabulated memories. (p. 429)

Mack also defends the use of hypnosis to recall memories, noting that although at times what is recalled under hypnosis is skewed, "it is wrong to assume that because hypnosis can interfere with memory it inevitably must do so" (p. 430). Mack further notes that "abduction material recovered under hypnosis parallels what has been obtained by conscious reporting" (p. 430) and feels that hypnotically derived materials should be compared with nonhypnotically derived material.

Although the significance of a particular piece of data may be debated, the basic facts of *most* medical accounts – whether told by medical personnel or others – are not disputed. So when depression strikes a man in peak form, or mania nearly costs a brilliant woman her career, or cancer strikes a woman who eats well and exercises, we do not take issue with the basic facts of these accounts as told by their authors. Our most fundamental assumptions about reality are not called into question.

This obviously changes when we come to stories of abduction. Even though we may not think that we know everything about reality, many of us nonetheless believe that we know enough to try to take authorial control away from Mack and his abductees.

I would argue that, to a large extent, our sanity is at issue, because our most fundamental understanding of reality is called into question by Mack's stories, and that is why accounts like Mack's rattle us like they do. Abduction stories call into question some of our most deeply held conceptions about reality and challenge

many of the most basic stories that ground our experience and sustain us.

Mack's stories of abductions highlight the role of stories in psychiatry and in our culture more generally. Stories can be sacred, and I would argue that our society's most fundamental stories about itself – those stories that ground it – are sacred in some way. I believe that Mack's work, unlike Styron's (1990) and Kaysen's (1993) and even Sacks's (1995), challenges and transgresses some of our culture's sacred stories. No wonder Harvard wanted blood.

BETWEEN FIRST AND THIRD PERSON

Lauren Slater's (1996) *Welcome to My Country* bridges the gap between first- and third-person accounts. In this work Slater writes about her work with the chronically mentally ill and, in a dramatic final chapter, writes about her own struggles with mental illness. Slater seems to feel that she has a special understanding of those who suffer from mental illness, but her tone verges into paternalism, condescension, and self-congratulation.

In one section of *Welcome to My Country*, for example, Slater speaks of finding the true meaning underneath the garbled, disjointed language of one of her clients. Slater begins (correctly, I would argue) by noting how her patient's inability to use language separated him from others: "His illness had resulted in the loss of language. The loss of language had cut him off not only from deep sources of self but also from his connections with others" (p. 97).

But then Slater describes how she stealthily looked at some writing this patient had done for a school assignment. "I peered at his sentences and paragraphs and saw glimmers of coherence in some of them, half-uttered themes that bled away into chaos" (p. 99). (I also take issue with many of the metaphors Slater uses, which obscure as much as they illuminate, but this is mostly an objection of style and I

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will not say more about it here.) She then continues:

What would happen, I wondered, if I acted as Joseph's prosthetic filter – a brain extension – clearing away from his sentences the verbal spasms and dust, the intrusions, that dirtied an intact meaning? Would an intact meaning then emerge? And, on a purely practical level, would I be able to help him pass his college course? (p. 102)

Is not this whole exercise of Slater's the height of presumptuousness – to read this man's work without permission and, even more, to edit it? After she made her changes, Slater showed Joseph what she had done. "Here," I said. "Here is what you did." He took the page I'd written on, scanned it, and his mouth dropped as he recognized his words, cleaned and shaped. "Oh," he said. "Oh. My. Mine." He smiled (p. 107).

Joseph did not give Slater permission to speak for him, so though she would like to think of herself as a coauthor of Joseph's, in fact she co-opts his writing and decides for him what Joseph really thinks and means. Joseph has probably already had more than enough people in his life telling him what it is that he ought to be thinking and feeling and writing. Isn't this just more of the same?

Ultimately, Slater seems pleased – too pleased – with how far she has come from her days of being a psychiatric patient, from her days of being diagnosed as having borderline personality disorder and an eating disorder. She constantly needs to reassure herself about her superiority over her patients. She speaks several times, for example, of being "Harvard trained," which she is – to a degree. Slater did receive a master's degree from Harvard, but her Ph.D. is from Boston University. Is highlighting her Harvard roots instead of her Boston University roots yet another way of reassuring herself, of propping herself up?

Furthermore, unlike many of the more humanistic caregivers, Slater says that she actually takes comfort in psychological jargon, because it further distances

her from her days as a patient. In so doing, I would argue, she negates what might be some of the better lessons of having been a patient. Has she asked herself how she felt, years earlier, when her caregivers spoke to her and about her in professional jargon?

In relishing her professional vocabulary, I would argue that Slater discounts her own experience of illness, much as she discounts the experience (and words and writing) of the patients with whom she now works. So, although having been a patient might make Slater better able to relate to her current clients, in the end it distances her from them, because she wants distance from who she was.

How sadly ironic, then, that Slater would like to be seen as someone with special gifts and abilities, largely because of her own bout with mental illness, but instead she dwells in stereotypes, self-congratulation, and paternalism, a particularly insidious paternalism because of its disguise as sympathetic understanding.

Perhaps Slater will be able to find some healing in telling her story in *Welcome to My Country*. If so, then maybe she will be able to drop her need for titles, jargon, and superiority – and accept herself a little more. Maybe then she will no longer need to separate so radically her former life and her current life, sickness and health.

CONCLUSION

Several questions emerge from the foregoing review. Who has the authority to narrate a life or an experience, especially of another person? And even if we do have the authority to narrative a given story, to what extent is it within our control? After all, to some extent, none of us is ever fully self-authored. Our stories are always told by many different sources – our economic circumstances, our genetic makeup, our families of origin, our race, and so on – beyond our control. None of us, therefore, is ever completely free (despite Sartre's contention to the contrary), and we are all a

combination of authorship from within and without.

Even so, most of us still like to have significant control over the stories that are told about us. As I stated earlier, I believe that is why Kaysen (1993), Styron (1990), and Middlebrook (1996) write the narratives they do. Their stories are attempts, I would contend, to speak with their own voice and not to have their words spoken for them from without.

Kaysen (1993) tackles her job in an innovative way by juxtaposing her official hospital record and her own account. In putting both accounts together into one narrative and publishing it under her name, we could argue that Kaysen has taken control of the *whole* story—both her part and that written from without—and claimed it *all* for herself. Perhaps this is the ultimate step toward self-healing—to be able to narrate one's own story, even the aspects of it that one might not have wanted or asked for.

Even though *Girl, Interrupted* incorporates two fairly disparate narratives, in no way should we ever delude ourselves into thinking that we have a complete account of that time of Kaysen's life. With narratives, "complete" can only remain an ideal pole on a continuum which is never, in fact, attainable.

So, for example, even after Middlebrook's (1996) confessional chapter in which she outlines the most personal and embarrassing aspects of her fight with cancer, it would be naive to think that everything that follows is completely true. Narrative accounts always include some things and exclude others (some consciously, many unconsciously), and no account is ever complete.

Because no narrative can be all encompassing and human beings always observe (and hence narrate) from a certain perspective—even those who would reauthor the stories of others—any notion of "objectivity" must be bracketed, and considered only as a theoretical construct. Nietzsche (1954) reminds us that "truths are illusions about which one has forgotten that this is what they are; metaphors

which are worn out and without sensuous power, metaphors—in moral terms: the obligation to lie according to a fixed convention, to lie herd-like in a style obligatory to all" (p. 47). Nietzsche suggests that what we consider to be "true" is merely a widely agreed upon lie. Do we participate and perpetuate the lie by wanting to recast troublesome material into well-worn metaphors and truisms?

Physicians must always take care to avoid considering their narratives as "true" and patients' narratives as "fictive" if the latter (as they often do) disagree with the former. Physicians should remember that, in spite of their expertise, their narratives are like those of the patient insofar as both are constructed or arranged—fictions—in the sense of "made or constructed" in the original Latin meaning of *fictio*. No narrative is ever complete or final, so an openness and willingness to revise one's narrative as warranted by the situation is essential to honest medical care. Indeed, ethical medical care demands this willingness, for without it the patient's autonomy can suffer under the oppressive weight of the supposedly "correct" and often more socially accepted narrative of the physician.

We also need to be sure that our medical narratives do not prevent us from full encounters with our patients' pain, because in their "objective" coldness and distance, our stories may well be institutionalized ways of avoiding pain and confrontation. We need to be able to hear with fresh ears.

In the end, stories are necessary for our survival because they provide boundaries for our world. As Nietzsche (1983) writes: "A living thing can be healthy, strong and fruitful only when bounded by a horizon; if it is incapable of drawing a horizon around itself, and at the same time too self-centred to enclose its own view within that of another, it will pine away slowly or hasten to its timely end" (p. 63). We must bind ourselves in a horizon in order to retain meaning in our lives—including some things within our horizon and excluding others, to designate some things as worthy of our attention and others as not—so

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that we are not lost in the chaos. In some sense, stories are all we have. They give us our meaning. They give us a past and a future. They bond us to one another.

In this essay I have argued that we need to remain humble about how we hear the

stories of others. Each of the works I have reviewed herein demands this. If we can do so, we will be better able to hear and respect our patients and form genuine connections with them.

REFERENCES

- CASELL, E. *Talking With Patients* (Vol. 1). MIT Press, 1985.
- HAWKINS, A. H. *Reconstructing Illness: Studies in Pathography*. Purdue University Press, 1993.
- HEIDEGGER, M. *Being and Time* (J. MacQuarrie and E. Robinson, trans.). Harper and Row, 1962.
- JAMISON, K. R. *An Unquiet Mind: A Memoir of Moods and Madness*. Knopf, 1995.
- KAYSEN, S. *Girl, Interrupted*. Turtle Bay Books, 1993.
- MACK, J. *Abduction: Human Encounters With Aliens* rev. ed. Ballantine, 1995.
- MIDDLEBROOK, C. *Seeing the Crab: A Memoir of Dying*. Basic Books, 1996.
- NIETZSCHE, F. On truth and lie in an extramoral sense. In W. Kaufmann, ed., *The Portable Nietzsche* (Kaufmann, trans.). Viking Press, 1954.
- NIETZSCHE, F. On the uses and disadvantages of History for Life. In R. J. Hollingdale, ed., *Untimely Meditations* (R. J. Hollingdale, trans.). Cambridge University Press, 1983.
- SACKS, O. *An Anthropologist on Mars: Seven Paradoxical Tales*. Knopf, 1995.
- SLATER, L. *Welcome to My Country*. Random House, 1996.
- STYRON, W. *Darkness Visible: A Memoir of Madness*. Random House, 1990.