The Story of “I”: Illness and Narrative Identity

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A bench on Hampstead Heath, overlooking London. I feel a bit like Rastignac, at the end of Le Père Goriot, pompously challenging Paris from the height of Père Lachaise cemetery: “A nous deux maintenant.” Even more like the neurologist Oliver Sacks, recounting, toward the end of A Leg to Stand On, his ascent to Parliament Hill, one of the highest spots on the Heath, after the abyss into which he had been hurled by a neurological “hole in identity” (186), following a leg operation. To tell a story, it would seem, is to model it on previous stories—a point made before me and to which I shall return later. I am writing in a period of relative remission—thereby probably lending support, almost against my will, to the phoenix metaphor I have stubbornly resisted in Arthur W. Frank’s stimulating 1993 essay on illness narratives. To this too I shall return later.

Illness. It happened in London, in the summer of 1998. I was spending a month there with my family, planning to stay for two additional months on my own to do research concerning my current project: the concept of narrative in various disciplines (historiography, psychoanalysis, legal studies). When I came out of the hairdresser’s one day, everything seemed alarmingly blurred, objects looked doubled, angles askew, people cut in the middle. Within a short while, I realized that I could no longer read, since lines suddenly collapsed into each other. My eyelids would droop without any warning, and I lost a sense of distance, so that an approaching bus could

Shlomith Rimmon-Kenan is Professor of English and Comparative Literature at the Hebrew University of Jerusalem, where she also holds the Renee Lang Chair for Humanistic Studies and currently heads the newly established School of Literature and Literary Theory. Her current research concerns the concept of narrative in various disciplines (psychoanalysis, historiography, law), an offshoot of which is her work on illness narratives.

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be quite near without my noticing. Tentative diagnosis: ocular myasthenia, an autoimmune neurological disease. Immediate result: I returned to Israel with my family after the first month, without doing any of the planned research.

Not the best illness for an academic, this interference with reading and writing (though I would be hard put to say which illness is best).2 “A death blow” was my first reaction, followed by an “identity crisis.” In retrospect, it seems to me that the sense of a rupture was caused by three main aspects of the condition: reading and writing, a professional necessity as well as an existential passion, have become virtually impossible. The need to control, both an asset and a problem in my professional and personal life,3 has itself been controlled by the unpredictability of individual attacks as well as the course of the whole disease. Intensity, associated in my mind with experiencing things fully, fighting circumstances rather than succumbing to them, and an uncompromising “all or nothing” temperament, had to give way to an acceptance of life “on a small fire.” The present text is an indirect working-through of my experience of discontinuity—indirect, because it is not a personal confession, but an exploration of the experience through a reading of other subjects’ stories about their illnesses. Without denying embarrassment as a possible motive for indirection, it (also) seems to me that this approach is particularly suitable for illness narratives, because what is problematized in the textual corpus I examine is precisely the “auto” component of “autobiography.”4

THE SCOPE OF THE STUDY

This study explores the interplay in illness narratives between continuity, its disruption, and the various ways of coping with the latter. What happens when the present is so different from the past that subjects experience themselves as “others”? And how does uncertainty about the future, or its blocking, affect the “identity” of ill subjects? How do ill subjects cope with the disruption of continuity? And how do they reconstruct their stories (to the extent that they do) as a result of the rupture? Is continuity replaced by a bipartite story, a “before” and “after,” with an unbridgeable gap between them? Does the breaking of continuity sometimes lead to a more radical fragmentation, and if so—is the term “narrative” still applicable? Or, conversely, is narrative a way of creating a new continuity to replace that which was ruptured?

I have chosen to study first-person nonfictional narratives, because my interest is in the ways that ill subjects themselves experience their illness and reconstruct (or avoid reconstructing) their life stories in relation to it.5 There are, to be sure, other kinds of illness narratives—e.g., a fictional story told in the third person by an extradiegetic narrator, like Tolstoy’s The Death of Ivan Ilych; a third-person account of a patient’s disease by the doctor(s) in charge of the treatment (a case report); a narrativization by a researcher on the basis of interviews with ill subjects; a narrative told by a significant other in the life of the ill subject (e.g., John Bayley’s An Elegy for Iris); or a collaborative story told by the ill subject together with a significant other (e.g., Joseph Heller and Speed Vogel’s No Laughing Matter, or—more poignantly—many AIDS memoirs, where the ill subject did not live long enough to complete the story).6
My decision to focus on first-person narratives is not a drastic limitation of the scope of the study, since illness narratives have become extremely popular in our time. This abundance is amenable to various explanations, of which I shall mention only those most relevant to my concerns:

1) The coexistence between the eruption and diagnosis of mass diseases (cancer, AIDS) with a significant improvement of medical technology frequently results in a prolongation of life. Today, there is a fairly large group of subjects who belong, in different degrees, to what Frank calls “the remission society” (The Wounded Storyteller 8–13). Illness narratives are one way of coping with the effect of long-term disease.

2) The almost impersonal aspect of modern medicine often provokes ill subjects to construct their illness as they experience it, often in conscious contrast to the medical “case report” where the protagonist is the illness, not the ill subjects, whose voice is silenced (or so at least they feel). The difference between the two types of account is often formulated as a contrast between “the voice of medicine” and “the voice of life” (Mishler; Hunter; Frank, At the Will of the Body, The Wounded Storyteller).

3) The physical and psychological changes caused by illness often create a sense of discontinuity in the subject’s “identity.” “I used to be Gilda Radner” is a moving expression of the experience by the well-known comedienne in her book about having cancer. Bridging the gap, making oneself available to oneself (Lorde 66) may be a conscious or unconscious motivation behind many illness narratives. Indeed, such motivation constitutes the specific focus of my study of first-person illness narratives.

Of the many narratives I have read, I have chosen four for this essay: Audre Lorde’s The Cancer Journals, Oliver Sacks’s A Leg to Stand On, Robert F. Murphy’s The Body Silent, and Christina Middlebrook’s Seeing the Crab: A Memoir of Dying. I prefer this selection of a few texts to a broad ranging exemplification, partly because the latter approach has already been impressively practiced by Frank (The Wounded Storyteller), Couser, and others. From time to time, I shall briefly mention other narratives, according to the needs of the argument.

SOME CONCEPTUAL ISSUES

An affinity between “narrative” and “identity” has been suggested in many disciplines. I wish to benefit from this insight and replace the term “identity” by “narrative identity.” I share with Ricoeur (Oneself as Another), MacIntyre, Bruner, Widdershoven, and others a nonessentialist view of identity. I also share their general contention (though there are differences in emphasis among them) that we lead our lives as stories, and our identity is constructed both by stories we tell ourselves and others about ourselves and by the master narratives that consciously or unconsciously serve as models for ours. Hence, “narrative identity.” Without following all the implications of a constructivist-narrativist view of identity, one of its advantages for me is a liberation from the thorny question of the adequation of illness narratives.
to reality. In other words, whether the narrators’ stories correspond to the ways others (professionals or friends) assess their behavior will not concern me here. What will interest me is narrative as a subjective construction of “identity.”

One of the main features, common to “narrative” and “identity” according to many theoreticians, is “coherence.”9 To give one example from many (though not all are normative in this way), here is Peter Brooks, a psychoanalytically oriented literary theorist: “Mens sana in fabula sana: mental health is a coherent life story, neurosis is faulty narrative” (49). Continuity, in my opinion, is one form of coherence, and the one that is specifically related to narrative, since it operates in time, time being a basic constituent of narrative. Continuity is a chrono-logical linkage between three temporal dimensions: past, present, and future. It is this linkage, characteristic of both stories and “narrative identity,” that is destabilized by illnesses of the kind with which my study is concerned. And it is the implicit or explicit assumption of continuity that underlies the experience of disruption as one of the traumatic aspects of illness.10

Disruption, however, is in no way exclusive to illness narratives, nor is it unique to traumas. According to Lieblich et al., the split into “before” and “after” permeates not only life stories shadowed by catastrophe, but all narratives characterized by a turning point, e.g., migration stories, conversion stories, etc. If so, what is specific to illness narratives? I wish to claim that the specificity of these narratives lies in the embodied nature of both continuity and disruption, indeed of the very notion of “narrative identity.” The bodily, visceral level entertains intimate relations with the ill subjects’ sense of time and hence with both narrative and “narrative identity.”11 It is this constellation that I wish to examine by means of the four narratives I have chosen.

**DISRUPTION**

Oliver Sacks, the famous neurologist whose books have become best sellers, suffered a serious leg injury as a result of a fall while climbing a high mountain in Norway. After an operation, he experienced a peculiar, until then little explored, neurological condition, characterized by a feeling of complete alienation from his leg, as if that “thing” appended to his body bore no relation to him. He experienced this disconnection as a veritable split in narrative identity—“not just a lesion in my muscle, but a lesion in me” (44)—a gap in time (carrying “a quality of ‘memory hole’” [77]), a hiatus in space (77), “a hole in reality” (68, 77): “The leg had vanished, taking its ‘past’ away with it. I could no longer remember having a leg. I could no longer remember how I had ever walked and climbed. I felt inconceivably cut off from the person who had walked and run, and climbed just five days before. There was only a ‘formal’ continuity between us. There was a gap—an absolute gap—between then and now; and in that gap, into the void, the former ‘I’ had vanished” (58). Thus, the rupture of the neurological contact between Sacks and his leg leads to a disjuncture of memory and consequently to “an absolute gap” between his present and past identities: not only the leg, but “the former ‘I’ had vanished.”
True, Sacks’s neurological condition involves a specific form of alienation, but similar effects of bodily disconnection on narrative identity are repeatedly emphasized by Barbara D. Webster, who suffered from a mild form of multiple sclerosis. One succinct quotation will suffice to make the point: “Disturbance of body image is very shattering. It disturbs the very experience and root of self” (124). While Webster explicitly refers to Sacks (88), Robert Murphy doesn’t, but the experiences he narrates are uncannily parallel. The analogy is all the more striking because of a major difference: Sacks recovered, whereas Murphy’s disease was degenerative and terminal. A professor of anthropology at Columbia University, Murphy had a tumor in his spinal cord that developed over fourteen years, rendering him totally paralyzed as well as incapable of speaking. With loss of feeling of his limbs, Murphy—like Sacks—also lost feeling for them. This emotional detachment from his body manifests itself in frequent references to “the leg” or “the arm” (86). He experiences a “radical dissociation from the body, a kind of etherealization of identity” (86), akin to an internal split: “gradually, my thoughts became disembodied, and I began to think of myself as if one part of me were perched over the head-board, watching the rest; it was as if it were happening to somebody else” (5).

In addition to alienation from the body, the gap between the lived present and memories of the past creates what Sacks describes as a “hole in identity” (186) and Murphy as “the damaged self” (73). The chapter bearing this title in Murphy’s book has for a motto the beginning of Kafka’s “Metamorphosis,” Gregor Samsa’s transformation into a gigantic insect, dramatizing a perception of the self as an allegorical embodiment of discontinuity, accompanied by a sense of dehumanization. And indeed Murphy relates physical damage both to severance from the past and to a diminution of self: “From the time my tumour was first diagnosed until my entry into a wheelchair life, I was increasingly afraid that I had lost much more than the full use of my legs. I had also lost a part of myself. . . . I had changed in my own mind, in my self-image, and in the basic conditions of my existence. . . . In middle age, the ground beneath me had convulsed” (73).

The shattering of narrative identity by the chasm between present and past may be exacerbated by a blocking of the future. “My history is no longer smooth and linear but bisected and polarized. And my long-range future does not really exist,” says Murphy (23). Christina Middlebrook, a San Francisco Jungian psychoanalyst, dying of Stage IV metastatic breast cancer, conveys the effects of the evaporation of the future both by way of an analogy with a fantasized soldier-double and directly: “We think neither of the future nor the past. The boy-soldier just focuses on living one more minute. A curtain has descended on the unknowable future. . . . Fantasies about being in control of my own destiny have evaporated like sea smoke. . . . I do not expect to know my grandchildren. I do not expect to grow old. I don’t even think about the Spring” (83–84).

After such disruption, what remains? Most illness narratives I have read tend, with different degrees of self-consciousness, to retell, restructure past memories and future expectations in a way that would cohere with the present, bridging the gap by creating a new kind of continuity, or a continuity governed by different emphases.
The pull toward coherence, continuity, transformation—motivated by a transitory or permanent need on the part of ill subjects to counter the rupture—is also affected by socially and culturally constructed expectations. Although this paper focuses on the subjective construction of identity, the constitutive role of cultural narratives deserves to be acknowledged and exemplified. In Western society, the first commandment of illness seems to be “get well!” (Talcott Parson’s famous dictum) and if this fails—at least conceal disruption under a semblance of continuity and/or victory. Personal narratives tend to either comply with or resist the dominant cultural norms.

A few examples from the corpus under consideration will suffice. Murphy poignantly analyzes the price the disabled have to pay for normal social relations: “they must comfort others about their own condition. They cannot show fear, sorrow, depression, sexuality, or anger, for this disturbs the able-bodied” (92). Then, switching to the personal, he adds: “As for the rest of the world, I must sustain their faith in their own immunity by looking resolutely cheery. Have a nice day!” (92). Webster bitterly diagnoses the conflict between her struggle to accept the limitations imposed by chronic illness and the American valorization of independence, self-sufficiency, control, activity, and progress (69–85). And Lorde indignantly recounts how the surgeon’s nurse urges her to wear a prosthesis: “You will feel so much better with it on . . . and besides, we really like you to wear something at least when you come in. Otherwise it’s bad for the morale of the office” (60). Lorde refuses to comfort the healthy about her disfigured condition. She wages a battle against the prosthesis as norm, because it reinforces the perception of women as sex objects, causes self-alienation by the gap between appearance and reality, and prevents amputated women from noticing each other and creating solidarity among themselves. Without artificially attempting to draw the line between the subjective and the cultural in the restructuring of narrative identity, let me proceed to explore the forms such restructuring tends to take.

FORMS OF NARRATIVE RESTRUCTURING

In “The Rhetoric of Self-Change,” Arthur W. Frank, one of the most moving and insightful writers about illness, distinguishes between two main narrative styles of self-change. The first reinforces “who I always have been” (42); the second is informed by “who I might become” (44). To use his own formulation: “But while the ‘have been’ discovers the old self already possessed the resources to deal with the epiphanal crisis, the ‘might become’ self discovers new resources that (so it believes) it did not previously possess” (42). On the one hand, I agree with Frank that narrative restructuring aligns the present of the illness either with the past or with the future, and my own discussion of specific narratives will retrace these two broad movements. On the other hand, I disagree with his contention in this early essay that “In most narratives of illness the author makes some claim for self change” (39) as well as with the near-generalization of the notions of “epiphany” and “phoenix” (41, 42). I postpone a discussion of this disagreement to the final section of my paper,
and would now like to make a few comments preliminary to my discussion of the reformation of narrative identity in specific texts.

a) Types of narrative are analytic categories. In reality, narratives never belong “purely” to one category or the other; each contains elements of the other, and the distinction is based on emphasis and dominance rather than on a clear-cut polarity.

b) These “non-neat” categories are also not static. In other words, the types of narrative should not be seen as representing types of narrators by way of stable association, but rather as stages in a process. The stages I have in mind are not normative, like those proposed by Kübler-Ross concerning adjustment to the knowledge of approaching death, but vary from one subject to another and within the same subject. Subjects are prone to telling different illness narratives at different stages of the illness, because their needs change with time. The act of narration is, at least partly, a response to the needs of the present, as distinct from an attempt at a faithful representation of the past. In long-term illnesses, the needs of the present are subject to alteration, causing a dynamic modification of stories constitutive of the relations between past, future, and present. The differences between retrospective and concurrent narratives are particularly interesting in this context.

c) Narrative continuity (and continuity of narrative identity) is created and/or maintained both by internal principles (e.g., a linear structure of the type: symptoms, diagnosis, remission, return to work, recurrence, etc.) and by a conscious or unconscious modelling of the specific narrative upon master narratives embedded in the culture. The role of master narratives in the formation of individual stories has been emphasized by Hayden White for historiography, Roy Schafer for psychoanalysis, Jerome Bruner for life stories and Paul Ricoeur for any narrative. Illness narratives are no exception. Thus psychologists Gergen and Gergen’s schemes for life stories (stories of progression, regression, stability, and various combinations among them) also inform illness narratives. Similarly, Couser discusses master narratives like “the conversion plot,” “the re-affiliation plot” (168–9), “the resurrection plot” (193), and the “return-to-roots” paradigm (213). Frank speaks about “phoenix narratives” (“The Rhetoric of Self-Change” 40 and elsewhere), as well as about “restitution,” “chaos,” and “quest” story-types (The Wounded Storyteller). Illness narratives are sometimes consciously modelled on a specific myth, like that of the Amazons of Dahomey in Audre Lorde or the struggle of the biblical Jacob with God’s angel in Frank (At the Will of the Body), but unconscious paradigms are no less central to the formation of continuity among as well as within narratives. The typology I am about to present can be seen in the same light—i.e., not as a classification for its own sake, but as a manifestation of the (re)constitution of narratives by patterns, schemes, genres, and myths that are “always already” there.

1) Realigning present and past

This category contains at least two subforms, one predominantly narrating the past in the light of the present, the other chiefly narrating the present in the light of the past. The difference between the two is one of emphasis.
a) Narrating the past in the light of the present

Motivated by a conscious or unconscious desire to (re)establish continuity between present and past, these narrators tend to emphasize elements of their past history that they did not stress before the illness, to create new connections among events, to change the balance between foreground and background, etc. For example, subjects who have perceived their life stories as progressive narratives (Gergen and Gergen, “Narratives of the Self” 254) and then, as a result of illness, find themselves entrapped in a bisected structure consisting of “before” and “after,” with an unbridgeable gap between them, may gradually reshape their narrative identities around a series of earlier crises experienced and survived. In this way, illness becomes one more episode in a recurrent structure, with the additional value of hope (this time, too, I’ll overcome). In Gergen and Gergen’s terms, a progressive narrative is replaced by a stability narrative in which, paradoxically, stability is a zigzag of crises and survival.16

Audre Lorde, the feminist American poet, uses this type of construction in a more radical way, seeing the present not only as a repetition of the past but as its intensification. In order to create continuity between her past and her present as a post-mastectomy woman, she reshapes the past around the parameter of difference. As a black, lesbian, feminist poet, “I am defined as other in every group I’m part of” (11). Being a woman with one breast becomes not only another example but an emblem of the otherness which has always characterized her life: “Because I am a woman, because I am black, because I am lesbian, because I am myself, a black woman warrior poet doing my work, come to ask you, are you doing yours?” (19). The image of a warrior is part of the master narrative which helps Lorde feel “ever so much more myself” (44), in spite of the changes inflicted by her illness and operation. She constructs her narrative identity on the basis of the myth about the Amazons of Dahomey who, at age 15, have their right breasts cut off to make them more effective archers. In a diary entry she muses: “How did the Amazons of Dahomey feel. They were only little girls. But they did this willingly, for something they believed in” (34; see also 27, 45). Continuity with the myth as master narrative reinforces the continuity in Lorde’s self-definition as a fighter, aligning her battle against “the politics of cancer” with her earlier wars against the discriminations of race, gender, and sexual preference.

Primarily an intensification of the past, Lorde’s illness is also seen as an occasion for changing the future: “I dreamt I had begun training to change my life, with a teacher who is very shadowy. I was not attending classes, but I was going to learn how to change my whole life, live differently, do everything in a new and different way” (12–13). The main transformations she hopes for are a change of priorities (18), greater selectivity in the choice of friends (47), an increased awareness (48), and even a translation of pain and fear into strength, wholeness, and creativity (13, 56, 64).17 Phoenix-like, “I have gained from the very loss I mourn. . . . I would never have chosen this path, but I am very glad to be who I am, here” (79).
b) Narrating the present in the light of the past

In the process of his gradual paralysis, Robert Murphy clings to professional activity as a way of proving to himself and others “that my life still had value and that some things remained unchanged” (69). He explicitly relates his behavior to a need to maintain continuity in his narrative identity: “these were ways for protecting the identity, for preserving that inner sense of who one is that is the individual’s anchor in a transient universe” (70). Even when his condition deteriorates further, he continues teaching, writing an academic book as well as The Body Silent, “driven now by an almost manic need for self-assertion and continuity,” defying—rather than denying—the illness (32). What is more interesting, however, is the way in which Murphy’s profession helps him redefine the present in terms of the past, narrating his ordeal as one more anthropological field study: “This book was conceived in the realization that my long illness with a disease of the spinal cord has been a kind of extended anthropological field trip, for through it I sojourned in a social world no less strange to me at first than those of the Amazon forests. And since it is the duty of all anthropologists to report on their travels, whether to Earth’s antipodes or to equally remote recesses of human experience, this is my accounting” (ix).

Murphy’s foregrounding of his profession is facilitated by the fact that both he and his wife are anthropologists, so that the personal and the professional converge in fruitful ways. Indeed, so prominent is Murphy’s profession in his self-narrative that Couzer labels his book “autoethnography” (205), and Murphy himself talks about the difficulty and challenges posed by being both the subject and the object of his research, both ethnographer and informant (3). This identity between “author and chief protagonist” (3) is carried to an extreme when Murphy moulds his present condition on the basis of an Ur-figure studied by anthropology, the shaman: “Paralysis is an allegory of life and entropy, and my search for their relationship places me in the role of the shaman, who seeks to reconcile the sick person to his illness by placing it in the context of timeless myth and belief” (171). Murphy almost uncannily associates his still body with specific shamans of a Peruvian Amazon tribe who “relate their myths while holding their bodies absolutely motionless” (171–72).

Just as Lorde’s consolidation of her present identity as an emblem of the past sometimes opens into a vision of a future change, so Murphy intersperses a story of continuity with phoenix-like affirmations of new meaning in life. What is celebrated in his case is a conversion of creativity from the physical to the spiritual: “But the essence of the well-lived life is the defiance of negativity, inertia and death. Life has a liturgy that must be continuously celebrated and renewed. . . . It is in this way that the paralytic—and all of us—will find freedom within the contours of the mind and in the transports of the imagination” (178–79).

2) Realigning present and future

Whereas the two previous types of narrative attempted to bridge the gap between present and past, the third constructs a relation between the present and a
future that can no longer be what the subjects imagined or used to tell themselves before the illness. And, indeed, this narrative type tends to emphasize not the continuous enchainment between temporal dimensions, but change, a turning point. In terms of Gergen and Gergen, this would be a story of regression followed by progression, and it is here that the phoenix metaphor is most appropriate.

Like the previous types of narrative, the turning point structure counteracts disruption, since instead of disconnected fragments, it discovers from within the present crisis a hidden potential in the past, capable of changing the future. Thus Oliver Sacks is convinced “that from now on I would be profoundly and permanently transformed” (144), a transformation affecting both his personal and his professional identity. On the personal level, he has discovered in himself unexpected patience, humility, and hope (81), and has learned to treat life “as the most precious of gifts, infinitely vulnerable and precarious, to be infinitely prized and cherished” (144). Sacks is conscious of the mythological master narrative which gives shape to his own story, “the journey of a soul into the underworld and back, a spiritual drama—on a neurological basis” (146). He narrates this drama in the explicitly religious terms of a “purgatorial dark night” (81) in which he lay waiting for a revelation: “but inwardly—I had to relinquish all my power and pretensions, all my adult, masculine enterprise and activity, and be childlike, patient, and passive, in the long night, this being the only proper posture of the soul at this time. I had to wait, to be still—for He was awaiting me” (80). The mysterious miracle (both words recur frequently) of healing is narrated in terms of rebirth, almost of an archetypal birth. The relevant chapter is entitled “Quickening”; Sacks sees himself as “Adam,” his recovery as “the first day of creation” (89), and the whole experience as a resurrection. His spiritual elation is symbolized in the topography of Parliament Hill, to which he walks from the Convalescent Home. The figurative significance of height is self-evident, but the implicit analogy between this high spot on the Heath and the Norwegian mountain on which Sacks fell may add a dimension of corrective experience to the second climb.

On the professional level, the transformation manifests itself both in Sacks’s attitude to his patients and in a redefinition of his field. As a result of his own illness, he understands “that one must oneself be a patient, and a patient among patients, that one must enter both the solitude and the community of patienthood, to have any real idea of what ‘being a patient’ means” (132). He hopes that he would now be able to enter imaginatively into the worlds of his patients and make himself accessible “in these regions of dread.”18 Furthermore, the specific nature of his illness made Sacks discover a new area with which neurology, as an empirical science, had not been equipped to deal. He calls this area “a neurology of self, of identity” (165) and devotes his professional life to its exploration.

“A neurology of self” is indeed a new field, but it is a field within neurology. And the miracle of recovery happens to Sacks when his leg starts moving to the rhythm of music, this “motor melody” (87) being the climax of his long-standing love of music. Thus, although A Leg to Stand On is classified here as a transformation narrative, it also has elements of continuity, characteristic of the two other types.
“CONTINUITY” INTERROGATED

During the long struggle to restructure my own narrative identity both directly and through the reading of illness narratives, as well as theoretical studies about them, a rebellious voice within me kept asking, in the spirit of Virginia Woolf’s “Modern Fiction,” “Is life like this? Must stories be like this?” Perhaps the assumption of continuity, on which both the experience and concept of disruption depend, is not universal. Do all subjects assume that they are—in principle—the same today as they were yesterday, ten years ago? Perhaps somewhere in the world there are Heraclitans, implicitly or explicitly convinced that the same subject cannot enter the same river twice, because both the latter and the former constantly change. And perhaps subjects who do not assume continuity in advance are relatively free of the drastic effects of disruption on the occasion of illness. Moreover, even subjects who have tacitly conceived of their lives (and identities) in terms of continuity may sometimes discover, due to the extreme rupture entailed by serious illness, that continuity has “always already” been an illusion. Such a discovery may lead to a retrospective interpretation, or renarration, of illness as an intensification of existential disruption, rather than as a sudden massive split. Perhaps disruption is the rule, rather than the exception (Becker). And perhaps this insight applies not only to the past-present axis, discussed so far, but also to the relations between present and future. Aren’t expectations for the future often replaced by a carpe diem attitude, and isn’t the “one day at a time” approach therapeutically valuable for subjects with terminal illnesses?

Beyond the experiences of ill subjects, misgivings also arise from a consideration of contemporary literature and thought. How is it that at a time when fragmentation is both prominent and valorized in postmodernist writing, illness narratives tend to preserve, even strive for, coherence and continuity? Wouldn’t narrative fragmentation be the most suitable form for the experience of disrupted narrative identity? And how can we account for the tension in constructivist theory between the postmodernist interrogation of “reality” and “identity” and the conservative emphasis on “coherence” and “continuity”?

These and other nagging questions persisted, although the growing number of narratives I have read repeatedly assumed continuity and tried to restructure narrative identity after its disruption by illness. It is therefore with a sense of relief, perhaps inappropriate to the sadness of the subject, that I came across Christina Middlebrook’s Seeing the Crab: A Memoir of Dying. Here, finally, is a text that partly dramatizes the disruption of identity by undoing some traditional narrative stitches. This undoing is most pronounced in the text’s intricate temporal organization and the occasional disassociation between personal pronoun and subject. Other aspects of the text, however, enhance continuity and coherence, warding off complete fragmentation.

In spite of the plethora of dates, a first reading of Seeing the Crab causes severe temporal disorientation. The frequent shifts between temporal dimensions, the many incongruities between narrative time and grammatical tense, and the seeming absence of a principle governing the irregularities create an effect of fragmentation, dislocating the reader’s sense of where s/he is in the unfolding of the story. Even a
critic as sophisticated as Couer suggests that Middlebrook dispenses with chronology (75), and I confess to a similar impression during an earlier stage of my own work on this book.

A painstaking juxtaposition of story time and text time (not just a rereading) reveals that there is method in the seeming chaos. Rather than obliterating the original effect of disorientation, however, a formulation of the complex organizing principle highlights the destabilization of neat linearity and the compression of time.

Seeing the Crab opens in the simultaneous present: the time is that of telling which—in this case—roughly coincides with the time of the events. Middlebrook is fifteen months after bone marrow transplant, in a period of remission, and is happy to note that “My hair reaches my shoulders now” (1). The simultaneous present, about a page long, then seems to disappear (it will return much later in the book), ceding its place to a long analepsis (2–136), narrating the progression of her illness from the time it was first diagnosed to the remission with which the text opens. Grosso modo, this long analepsis is told chronologically, but the chronology is destabilized in three main ways. First, it is frequently interrupted by memories—analepses within the analepsis—of pre-illness events, and these are conjured up by way of association, skipping from one temporal dimension to another, without any respect for chronology. The second-degree analeptic segments are often so long as to make the reader forget (at least temporarily) their second-degree status, and the return to the first-degree analepsis is often confusing. Second, both the main analepsis and the second-degree analepses are sometimes told in the past tense and sometimes in the present, adding perplexity to confusion. As distinct from the opening of the text, these analepses are characterized by what is known as the “historical present,” creating a dramatic effect of intensity and “presentification” (Cohn 99). Narratively, the historical present is not a present, but a convention for telling the past vividly. Nevertheless, the frequent tense-switching in Seeing the Crab creates extreme disorientation. Third, and most confusing, are instances where a second-degree analepsis, told in the present tense, is followed by a return to the first-degree analepsis, also narrated in the present (or vice-versa). Here the change in narrative time is not accompanied by a change in grammatical tense, and the effect is most unsettling.

“Time has lost its linear qualities,” says Middlebrook (163) in narrating the effects of her illness. Taken metanarratively, though not framed this way in its local context, this statement forcefully illuminates the temporal irregularities I have attempted to describe. At another point, Middlebrook emphasizes the importance of reconstituting memory in the effort of reconstructing identity. “The experience,” she says, “returns in pieces” (70). Whereas the attempt to reconstitute memory may explain why, in remission, she resorts to analeptic narration, her rendering of the retrieval process performs not only her ordeal but also that of the reader trying to put together the events of her story. “In pieces” is the return of her experience, the temporal organization of her text, and its reliving in the reading process.

The exact point at which the main analepsis ends and narrated time joins the time of narration is imperceptible. Chapter 14, revolving around a false alarm, contains references which echo the book’s opening: “I’m going to lose my hair again,
just when I have finally retrieved the hair I used to have” (143). And by p. 154, we are about five months later than the beginning of the text: “Now, nearly two years post transplant.” From now on, the text continues in the simultaneous present: the time of writing, which is also the time of preparing for death. The blocking of the future provokes a carpe diem attitude, discussed earlier in my paper. Recalling a similar inclination in The Diary of a Zen Nun, Middlebrook says: “Today I am alive” (12). And at a later stage, in connection with a shopping spree, “I want all these things now. The virtue of waiting has evaporated” (157 emphasis original). In context, these statements are not metanarrative, and yet their implications for the use of the simultaneous present are unmistakable: when the future is curtailed, time is compressed into a fleeting “now.” That “now” is both the time of experience and the time of writing is made explicit on several occasions: “I feel a great pressure of time. I want to finish my writing” (142; see also 143, 153). Predominantly in the simultaneous present, the extended final section (about 70 pages) also contains a few past-tense analepses, mainly to earlier stages of the illness, but they are short and do not occupy center stage. What is more interesting is the intertwining of the simultaneous with the generalized present, as Middlebrook narrates her own experiences together with existential meditations about accepting the inevitable and “making the darkness conscious” (212).

If temporal contraction and dislocation dramatize discontinuity, shifts in personal pronouns correspond to the dissociation of narrative identity. Narrating in retrospect (but in the historical present) the twenty-five days in which she lay in an isolation room during stem cell rescue, Middlebrook conveys the experience of split identity by switching from the first person to the third: “The zoo creature is very dopey. Its left eyelid sags. Its back is covered by a hideous, pussy rash that itches. . . . Worst of all, the zoo creature cannot think or remember. It says things in a language that makes no sense. It cannot watch or understand a video. . . . It does not know what day it is or whether it is day or night” (55–56). The connection between narrative identity, embodiment, and temporal continuity—discussed earlier in my paper—is salient in this passage. Having lost it, Middlebrook is not only “other” to herself, but also inhuman, an “it,” a “zoo creature.” Later, when she sees a photograph of herself taken during those isolation days, she fails to recognize herself: “She is so ugly. She is so sick” (72 my emphasis).24

In spite of its many discontinuities, Seeing the Crab is not fully fragmentary. Temporal disruption is often countered by “signposts” like “I remember” (27, 80), “Memory” (109), and “My recollection of the beginning” (32), situating the reader in time. Textual fragmentation is suspended by recurrent motifs and symbols, of which I choose only the crab, and only two instances where present illness and past health are interlocked. Recalling the initial diagnosis, Middlebrook links the dreaded illness with the creature from which its name derives: “even then I said I had to get to know this cancer, this vile crab, and make it part of who I am” (4). Later, she narrates a pre-illness memory of her first husband teaching the family how to reach into the tidal pool and grab a crab with a bare hand. The narration, however, is full of allusions to the later illness: “The crab is a shifty beast, its eyes attached to its body like headlights. Like cancer, it never takes the direct path, preferring to move side-
ways and furtively” (14). If internal cohesion is enhanced by recurrent motifs, master narratives, relating her illness to war in general and to specific wars in particular (Vietnam, Bosnia, the Middle East), create continuity between her personal reality and other traumas in world history. Seeing the Crab is thus only partially fragmented, and I have not found examples of more extreme dissolution in the illness narratives I have read.

Could there be an unconscious bias in the corpus I have read, leading to an almost total exclusion of fragmentariness? Indeed, there could. First, the narratives I have read are on the whole retrospective, and narrating after the event tends to be more coherent than telling during the suffering, as is evidenced by the concurrent segments of Middlebrook’s text or the diary entries in Audre Lorde. Second, I have studied written narratives, not oral testimonies or interviews, because the former are more amenable to my competences as a literary narratologist, while the latter require skills more fully developed in other disciplines. For reasons I shall discuss soon, writing seems to invite a tighter organization than oral narratives (see Charmaz; Langer; Frank, The Wounded Storyteller; Becker). Third, the texts I have read are not only written but published, and publishers tend to favor the nonfragmentary, for reasons of intelligibility, but also because coherence is likely to be interpreted as a sign of control or mastery, and readers usually prefer stories of triumph (or so publishers seem to believe). Moreover, most of the published narratives I have read were written by authors who had experience with writing before they became ill: poets, novelists, journalists, academics. It is understandable that such professionals resort to writing more “naturally,” but this too may contribute to the slant in my findings.

Given the paucity of fragmented narratives in my corpus, why am I so obsessed with fragmentation? The foregoing methodological reflections have attempted to explain the difficulties in finding full fragmentation in written and published illness narratives. At the same time, however, they have inadvertently underplayed the basic assumption discussed earlier in this paper, namely that the concept of narrative is not limited to either written or oral discourse. Narrative is one mode of experiencing, perceiving, and interpreting the world, as well as negotiating identities. Narrative structuring is an ongoing process, whether conscious or unconscious, which need not become audible; a construction of self-stories for ourselves and sometimes for others. In ill subjects (and perhaps not only in them), this process contains phases of disintegration and fragmentation as well as moments pulling toward continuity and coherence, and these may even be simultaneous. Fragmented narratives may become unintelligible and threatening, and hence risk remaining unheeded. Wittingly or unwittingly, they also subvert the cure-promising authority, thus provoking anxiety which sometimes leads to their being “rewritten” by physicians and other care-givers. It is for these reasons that I feel an ethical commitment to such narratives, both as lived experience and as written texts. Furthermore, the possibility of fragmentation seems to me to lay bare the ill subject’s vulnerability, thereby suggesting the limitations, perhaps even the hubris, of the better-structured narratives with which the bulk of this paper is concerned.

Motivated by a similar moral impulse, Arthur Frank eloquently calls for “honoring the chaos story” (The Wounded Storyteller 109), which he defines as follows:
“Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernable causality” (97).27 However, in the same breath, Frank also claims that chaos narratives are incompatible with writing, perhaps even with telling. “Those who are truly living the chaos cannot tell in words. . . . The chaos that can be told in story is already taking place at a distance and is being reflected on retrospectively. . . . Lived chaos makes reflection, and consequently story-telling impossible” (98). Telling, and even more so writing, it seems, is a way of taking control, creating order, thus keeping chaos at bay.

It is the implied redemptive or therapeutic role of telling and writing that I wish to interrogate. I have argued elsewhere (“Narration as Repetition”) that while narration may lead to a working through and mastery, it may also imprison the narrative in a kind of textual neurosis, an issueless reenactment of the traumatic events it narrates (or fails to narrate). I would like to challenge Frank’s view of telling and writing as triumphs over dissolution by the possibility (not the necessity) that both may sometimes be entrapments in the chaos they tell. This is evident in many diaries written during the Holocaust, as distinct from the better-known retrospective testimonies (see Langer), but it is also noticeable in some literary works by Faulkner, Grass, Beckett, Morrison, and others. The insistence on the incompatibility between chaos and narrative, I suggest, may blind us to parallel instances in illness narratives.

This brings me to the disagreement I alluded to earlier with Frank’s use of the notions of “epiphany” and “phoenix.” True, between “The Rhetoric of Self-Change” and The Wounded Storyteller the phoenix metaphor has shifted from an almost generalized characteristic of illness narratives to one type of “quest narratives.” Both notions are now presented with a reservation to which I resonate: “The risk of quest stories is like the risk of the Phoenix metaphor: they can present the burning process as too clean and the transformation as too complete, and they can implicitly deprecate those who fail to rise out of their own ashes” (Wounded Storyteller 135). However, I feel that many of the qualities earlier attributed to the phoenix are now transposed to writing, owing to the coherence it seems to entail. Clearly, Frank has no desire to marginalize disintegrating ill subjects. Nevertheless, I am afraid that his emphasis on the incompatibility between “chaos” and “narrative,” together with his valorization of esthetic control, may unintentionally have a marginalizing effect. About “enlightenment,” a rough parallel to Frank’s “epiphany,” Middlebrook says:

Faith [a member of the Cancer Support Group] wonders why she doesn’t feel enlightened the way all other cancer survivors who tell their stories do. Other cancer survivors, the ones who write books, who speak of cancer having rearranged their priorities, bettered their relationships, made them grateful for each day. She asks whether anyone else in our breast cancer support group feels thus enlightened. Enlightenment. I try to picture white clouds on a blue sky. . . . Enlightenment, I think, equals peace, serenity, tranquility. The list is long: gratitude, awe, acceptance. I hate that list. (149)

And later: “I cannot exercise. I cannot make dinner. I cannot play scrabble. I
cannot read. Enlightenment is worth none of this pain” (166). The early Frank would probably call Middlebrook “a reluctant phoenix” (my emphasis), whereas she implicitly refuses the category of phoenix, suggesting that illness need not lead to self-change or transformation. My own concern is by no means to reject the possibility of “phoenix,” or of coherence, only to make room for illness narratives without epiphanies and for writing that does not overcome chaos.

EPILOGUE

Turning back upon myself, I realize that the foregoing defense of fragmentation as well as the essay of which it is a part are written in a nonfragmentary, coherent, systematic way (too systematic, some would say), appearing to belie the argument presented. However, it is precisely this seeming aporia that manifests the interplay, discussed earlier in the paper, between alternative narratives at different points of the illness, and even at the same point. On the one hand, the very writing of this paper, no less than its structure and style, can be taken as a much-needed affirmation of continuity in my professional identity (obviously going beyond the professional). On the other hand, I have allowed myself to introduce the personal and have chosen a subject closer to the bone, not strictly within the formal areas of my expertise. These are aspects of a transformation narrative I occasionally like to tell myself about my experience of illness. At the same time, periods of disintegration do return, and my defense of fragmentation is at least partly motivated by the desire to legitimate and respect them. Whether the construction of continuity or transformation is an attempt to control the anxiety of disruption, or—conversely—the emphasis on fragmentation is a defiance of the constraints of mastery is not for me to say. All I can say is that by analyzing similar processes in the narratives of others, I hope I have done something toward a mutual illumination of their predicaments and mine.

ENDNOTES

1. I am grateful to Shuli Barzilai, Bill Daleski, Michal Govrin, Ruth Ginzburg, Elizabeth Freund, Arthur Frank, Sharon Kaufman, Jim Phelan, Shimon Sandbank, Leona Toker, and the anonymous reader for Narrative for their comments at different stages of the project. Special thanks to my assistant, Ayelet Schnur, whose help has been invaluable.

2. It is customary in sociological and anthropological literature to distinguish between “disease” (the objective medical condition) and “illness” (the subjective experience of living through a disease) (e.g., Frank, At the Will of the Body 12–13; Hunter; Couser 10). Readers aware of the growing body of disability studies may wonder why the term “disability” does not appear in this distinction. To my knowledge, there is no clear-cut definition of the differences between “illness” (or “disease”) and “disability.” The categories sometimes overlap, but—depending on who defines them—do not fully coincide. Many of the points I make are also relevant to disability, but the central distinction for my purpose is between the medical condition and the subjective experience of living through it. I cling to “illness” because (as my parenthetical references show) it has come to evoke that experience.

3. This need is probably one of the explanations of my attraction to structuralism in the seventies.
4. For an interesting defence of the indirect in the context of feminism, see Felman 13–14. Interestingly, my raw, confessional scribblings during the early period of the illness came out in Hebrew—my mother tongue, seldom my vehicle for academic writing (I am somewhat ashamed to admit).

5. Of course, the distinction between “fictional” and “nonfictional” is notoriously problematic these days.

6. For an interesting study of AIDS in relation to authoring, writing and reading, see Chambers 67-75. See also Peggy Phelan’s response in the same issue, 77-87.

7. Not everyone would agree with my understanding of MacIntyre’s position on “narrative identity.” For a different view see, for example, Meagher 65–67.

8. The authors whose narratives I discuss do not theorize essentialist/constructivist positions and often talk about “self,” “self-image,” “identity.” My analysis will keep to their own terminology.

9. Some theorists (e.g., MacIntyre) talk about “unity.” I shall avoid discussing the differences between “coherence” and “unity” in order not to blur the focus of this essay.

10. In the final section of the paper, I shall question the assumption of continuity.

11. For similar positions, see Becker 11; Frank, _Wounded Storyteller_, especially his term “body-selves.”

12. Frank borrows the notion of epiphany from Denzin (70) and the metaphor of the phoenix from the medical ethicist William May. Couser has a similar phenomenon in mind when he speaks about the “comic plot” of illness narratives (5, 39, and elsewhere).

   Frank proposes two additional categories: “cumulative epiphanies” and “reluctant phoenixes.” The last category refers to narrators who do not see their illness as an occasion for change. These, it seems to me, need not be called “reluctant phoenixes,” as if they resist doing what they are expected to, but, for example, “narratives without transformation.”

13. Frank calls his categories “ideal types” (_Wounded Storyteller_ 76 and elsewhere), and my position is similar to his, even though my terminology is different.

14. It is quite possible that Kübler-Ross did not mean the stages to be normative, but this is the common reception of her work.

15. These examples will be discussed later.

16. As Michal Govrin pointed out in a personal communication, this model is often employed in telling Jewish history.

17. Barbara D. Webster similarly writes: “I think, for me, the knowledge that I have MS has acted primarily as a great clarifier . . . has made me want to be even more clear about exactly what life is and to be direct in my response to it” (34). She too speaks about changes in priorities (34–35) and in relations with friends (55–59).

18. Judging by his later books, this hope has indeed been realized. Couser, by contrast, is critical of what he sees as Sacks’s tone of “self-congratulation, if not self promotion” (188).

19. I am aware of the “conservative,” mimetic assumption underlying this question.

20. I say “roughly” because I do not want to claim that she necessarily writes _during_ an event or experience, but in Middlebrook’s simultaneous present narrating and events are parallel, and the temporal distance between them is minimal.

21. Cohn has many interesting insights into the historical vs. simultaneous present in fiction, but her main concern is with texts which are narrated in the simultaneous present throughout.

22. For a similar point about other texts, see Cohn 99, note 13.

23. I am aware of the fact that “in pieces” can also be taken, less dramatically, to mean “gradually.”

24. See also 168 for the use of the third-person as an expression of alienation from her past identity.
Another form of split identity, which I do not discuss, emerges from the Jungian distinction between “Ego” and “Self.”

25. It is interesting that she also wonders whether embracing symbols “of battle or victory, of hero or martyr” may simultaneously serve the opposite purpose, i.e., “to camouflage the tininess of my own life” (197).

26. See also Langer on holocaust testimonies.

27. Later, Frank quotes a passage from an interview conducted by Kathy Charmaz, and part of his “diagnosis” is likely to be problematic for narratologists. “The second feature of chaos narrative in Nancy’s story,” he says, “is the syntactic structure of ‘and then and then and then’” (Wounded Storyteller 99). For a narratologist, mere sequence without causality would not turn a discourse into “an anti-narrative” (98). Ever since Forster’s classical (and problematic) distinction between “story” and “plot,” a purely additive organization is seen as one type of narrative (although, according to Forster, an inferior one). But my main interest here is not a narratological disagreement with Frank.

28. Nevertheless, there are moments of “enlightenment” in Seeing the Crab.

29. See note 12 above.

WORKS CITED


