Restoring the Patient’s Voice: The Case of Gilda Radner

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In the past few years, the medical case report has been studied as a document that evidences the way the patient and, by extension, the experiential and subjective aspects of an illness tend to be marginalized in contemporary medical theory and practice. First-person narratives about illness, our popular “pathographies,” may in part represent our attempt as a culture to respond to this problem of “the vanishing patient.” A rich source of information about patient experience, pathographies can be useful to us in locating specific issues in the medical enterprise that need understanding and perhaps require correction. Gilda Radner’s It’s Always Something demonstrates how two important issues—both neglected in the conventional medical history—powerfully affect the medical enterprise: the hopes, expectations, and wishes of the experiencing patient, and the perceived attitudes and demeanor of the patient’s physicians. The restoration of patient and physician to the “history” is important not only because it reminds us of the personal dimension of the medical enterprise, but also because it alerts us to problems of attitude and action that bear directly on diagnosis, course of treatment, and the therapeutic transaction.

CASE HISTORY AND PATHOGRAPHY

Gilda Radner is best known to most of us through her outrageously comic impersonations on “Saturday Night Live.” But she is also familiar to many readers as the author of a pathography describing her experience with cancer, It’s Always Something [1]—a book that remained for months on The New York Times best-seller list. What lessons can this gifted comedienne teach about serious issues in medical practice? And what can a popular account of one person’s experience of illness add to the medical record and the concepts of disease and treatment which that record represents? It will be my argument that books such as It’s Always Something form a significant and important part of the human record of disease, complementing the case history or medical record by filling in crucial gaps in its reporting and pointing to real and acute problems in medical practice which the case report omits or ignores.

The need for such a supplementary record has clearly emerged in recent studies which analyze medical histories as “texts” that can reveal much about the values, priorities, and ideological agenda of the medical profession [2–12]. Many commentators conclude that the case report, by its very structure, validates a depersonalized and technological approach to patient care; others fault the medical history for its failure to convey any genuine sense of patient experience. But there is another kind of illness narrative in which patient experience is given a voice. Popular literature registers an analogous though very different response to the problem of “the disappearing patient” in the medical enterprise. A surprising number of patients are taking up pen and paper and writing book-length descriptions of their illnesses and treatment. The remarkable popularity of “pathographies,” personal accounts of
illness written by patients or a patient’s friend or relative, may represent our response as a culture to this problem of the vanishing patient. Unlike their medical counterparts, these lay writings privilege the phenomenological, the subjective, the experiential side of illness. Pathography restores the patient to the medical enterprise, and it places that person, not disease and treatment, at the very center [13].

It is important that we bear in mind the fictive quality of both pathography and case history—the fact that the pathographical rendering of an illness experience is not the “real” story any more than is the case history or medical record. As critics and theorists of autobiography and biography have shown us, all forms of life-writing inevitably alter experience in that their authors are selective in what they record, find an order in the incidents and events selected, and impose meaning on the material so ordered. This transformation is certainly true of the case history, which Kathryn Hunter has discussed (in its oral form) as a narrative exercise in interpretation and thus subject to the literary critic’s analysis: “... case histories are themselves readings and interpretations of events as they have been represented in patients’ narratives or as they have left their marks on patients’ bodies” [14:p. 8]. The medical case history or case presentation is a highly formalized interpretation of the patient’s story, but it does not follow that the patient’s written narrative is the “true” version of the experience. Pathography must be appreciated not as a genre providing an accurate record of an experience but as an interpretation, a construction, that can give us important information about the subjective dimension of an illness [13].

In several ways pathography can be viewed as a complement to the medical history. Though both genres concern the sickness and treatment of a specific individual, they are radically different in subject, purpose, structure, authorial persona, and tone. The subject of the case report is a particular biomedical condition, but the subject of pathography is illness and treatment as endured and understood by the ill person who is the author. The purpose of the case report is to record diagnosis and treatment, whereas the purpose of pathography is to draw out the meaning of the author’s experience. The medical report is usually composed of brief factual statements about symptoms and body chemistry, but a pathography is an extended narrative situating the illness experience within the author’s life and the meaning of that life. The ideal medical report disavows any authorship at all (the first-person pronoun is rarely used); on the other hand, the authorship of a pathography is never in question. The case report regularly omits any reference to the physician’s emotional response or intuitive insight and rarely mentions the subjectivity of the patient. Pathography, at the other extreme, tends to focus on the subjective components of a medical experience, sometimes with unavoidably theatrical results. But the drama of a pathography is no worse a distortion of reality than is the biomedical myopia of the case report. Indeed, if pathography is directly compared to the case history, the patient’s own account will appear not so much a grossly exaggerated revision of what happened as a corrective to the stark, depersonalized account of tissues and tests written up by medical personnel. Case report and pathography function as mirrors set up at an oblique angle to experience: each one distorts; each one tells the truth.

THE STORY: OSCILLATING BETWEEN ORTHODOX AND ALTERNATIVE THERAPIES

Radner’s pathography is a narrative that not only vividly evokes patient experience, but also illuminates the way that experience can impinge on the course of illness
and treatment. It is easy to be caught up in her description of her cancer experience: 
the dramatic interest such stories of grave and threatening illness excite in a lay 
reader here combines with liveliness and humor and the sense of a unique and vital 
personality. Yet the narrative also reveals, as we shall see, a disturbing and repeated 
pattern of real importance to the course of Radner's illness and treatment. The 
theme of illness works its way into this narrative slowly, and relatively late, beginning 
with symptoms of fatigue and a vague malaise. Radner is prompt in seeking medical 
advice, but internist, gastroenterologist, and gynecologist all fail to arrive at a correct 
diagnosis for her problems. And so does she, convinced that the diagnoses they give 
of Epstein-Barr virus and mittelschmerz are “fitting diseases for the Queen of 
Neurosis” [1:p. 52]. Frustrated, she visits an acupuncturist and then a holistic doctor, 
who advocates coffee enemas and protein supplements, “hundreds of little pills and 
bottles, holistic drops and bags of seeds and leaves and cans of food supplements” 
[1:p. 66]. But, more important, he also calls her daily to find out how she is feeling, 
and this contact seems to her of more importance than the particulars of treatment. 
Her remarks on his solicitousness are bracketed by her observation that “this holistic 
doctor was paying attention to me” and the conclusion she draws, that “At least he 
and the acupuncturist were taking me seriously” [1:p. 66]. At one point, suffering 
from severe stomach pains, she visits three different kinds of doctors within a five-day 
period: the acupuncturist sticks needles in her stomach and gives her an abdominal 
massage, the holistic doctor suggests a colonic to clean out the bowel, the internist 
gives her a gamma globulin shot and a prescription for laxatives. Radner here admits 
to a superfluity of doctors and treatments, and raises the question as to whether she 
ought to “tell the doctors about each other.” But she apparently does not. Instead, 
she chooses between them, deciding on the holistic doctor because, she repeats, he 
“was paying the most attention to me” [1:p. 67]. 

This early picture of the way Radner oscillates between orthodox and alternative 
medicine during the initial stages of her illness in fact becomes a pattern, repeated 
again and again as the narrative and the illness progress. The notion of a patient, like 
“Everyman” in a medieval morality play, poised between opposing systems of health 
care treatment (orthodox and alternative) may seem anomalous to many physicians, 
but a survey of pathographical narratives will confirm this situation to be an accurate 
depiction of the way a surprising number of people today deal with their medical 
needs. 

Radner’s reasons for alternating between orthodox and alternative treatments are 
as significant as the fact that she does so. It is important that she should perceive her 
acupuncturist and holistic therapist, unlike her orthodox doctors, as “taking me 
seriously” and “paying attention to me,” for this perception underlies and justifies 
her experimentation with alternative therapies. This course of action, too, becomes a 
model for the future. In every instance where she turns to alternative therapists, she 
does so not so much because she believes in what they are doing as because they are 
more attentive, more personal, more hopeful than her orthodox physicians. 

Eventually her symptoms reach a point at which hospitalization becomes neces-
sary. When tests finally reveal that she has ovarian cancer, Radner consents to an 
immediate hysterectomy and subsequent chemotherapy. Again she turns to alterna-
tive treatment modalities, but, this time, as complements to, rather than substitutes 
for, orthodox medical treatment. Significantly, it is her oncologist who suggests that 
she see a therapist specializing in relaxation and visualization exercises. Readers will
vary as to their judgment of the wisdom of this advice. On the one hand, the oncologist, by recommending such treatment, could be seen as legitimizing experimentation with further alternative therapies, some of which might be fraudulent, some even harmful. On the other hand, given Radner’s already established interest in alternative therapies, this doctor should be commended for having at least achieved the kind of rapport with his patient that allowed him to see beyond the tumor and the chemotherapy. Radner herself observes approvingly that the oncologist “understood that he was treating the mind as well as the body” [1:p. 75].

Radner does consult the therapist he recommends, and she becomes deeply involved in attempts to get well by the use of visualization and positive thinking. These attempts are reinforced when she joins a cancer support group, which instructs participants in guided imagery, visualization, and relaxation and teaches them how to “take control” of their recovery. She begins wearing healing crystals “as reminders of the body’s and the spirit’s desires and capacity to be well” [1:p. 174]. She makes up a chant—“I am well, I am wonderful, I am cancer-free”—which she uses as much in an attempt to drive out negative thoughts as to affirm the positive: “I’d have these words to think so that the cancer thoughts couldn’t get in” [1:p. 178]. She finds herself smiling as she repeats this chant, remarking: “I knew that smiling a lot helps fight disease” [1:p. 178]. Despite the nausea, hair loss, and fatigue she experiences as side effects of the chemotherapy, her spirits are high.

At this point her narrative changes direction. She agrees to a second-look surgery, though she worries “that if they did find more cancer... it would destroy my faith in my own sensibility and my sense about my body” [1:p. 181]. Unfortunately, the biopsy reveals two microscopic cancer cells, and her physicians want her to begin another round of chemotherapy. She is crushed by this result, “totally shattered” and “terribly depressed,” and her hopeful approach begins to backfire: “I couldn’t deal with the premise that after you have done everything right, done everything you possibly could do—positive thinking, crystals, visualization, psychotherapy, gotten your head into a wonderful place, everything—suddenly it turns out that perfect behavior might not have worked” [1:pp. 191,194]

Radner deals with this new stage of her illness at first by combining chemotherapy and macrobiotics. The therapists for each kind of treatment are starkly contrasted: they emerge in the narrative as life and death, hope and despair. Her macrobiotic counselor restores her optimism and her good spirits when he assures her that she has a chance to recover, but her oncologist, in withholding the hope she so desperately craves, seems to exacerbate her suffering: “that doctor,” she observes, “is death to me. He looks at me and he sees me dying” [1:p. 243]. Not unpredictably, she walks out on the oncologist. But, despite a frantic and slavish adherence to a macrobiotic life style (she even has a live-in macrobiotic cook), complemented by sessions on psychic healing and a series of interviews with the holistic therapist Lawrence LeShan, her condition does not improve, and by now her weight is down to 95 pounds. Once again she changes therapies, terminating the macrobiotic diet and returning to an orthodox cancer specialist to begin another course of chemotherapy—a treatment which she is told has an 85 percent chance of success. Radner interprets this possibility as a cure: “He was talking about restoring my future, not just prolonging my life... he believes that I will get completely well” [1:pp. 256,266]. At the conclusion of the book, she is still hopeful, though guardedly so, of recovery. Several months later she is dead.
THE PATIENT: “HEALTHY-MINDEDNESS” AND HOPE

It is highly unlikely that a patient’s medical record will include the issue of alternative treatment at all (most patients do not tell their doctors about this course of action) or the patient’s dissatisfaction with his or her physician. Radner’s pathography thus supplements the medical history in that it not only documents the complete course of treatment but reveals the patterns and motivation behind her use of alternative medicine. Moreover, beyond this, her pathography makes us realize the importance of the patient’s expectations as to treatment and the doctor’s attitudes and personal style—two elements the medical record inevitably omits—to the course of illness.

One response to her book will focus on this patient’s expectations, hopes, and wishes, perceiving this “case” as disclosing the dangers of the current belief that right attitude—the will to live—can effectively alter the course of an illness for the better. This belief is extremely widespread, at present, in lay perceptions of illness and treatment. It is a component of an approach to illness and treatment that might be called “healthy-mindedness” [13: chapter 5]. Represented by the works of such popular authors as Norman Cousins, Carl and Stephanie Simonton, and Bernie Siegel [15–19], a “healthy-minded” perspective on illness and treatment emphasizes psychological factors in the etiology and treatment of illness and regards the attempt to identify with and nurture the life-enhancing aspects of self and body as of primary importance. Right attitude is considered a highly important therapeutic tool, and a good deal of significance is assigned to belief in oneself and active participation in and control over treatment.

Radner’s experimentation with alternative therapies of various sorts illustrates this healthy-minded perspective. Thus, as a supplement to chemotherapy, she engages in visualization exercises “to imagine I was helping the chemicals fight the cancer cells” [1:p. 81]. Her therapist, Radner reports, tells her that “if you visualize the cancer cells and see them as evil and visualize them being removed from your body, you are supporting the actual process” [1:p. 83]—a virtual manifesto of healthy-mindedness. As a participant in a cancer support group, Radner adopts a new attitude toward her physicians, demanding explanations of her condition and the treatments she is given: “... I became an expert on my own case. I started to regain control in my life, to take charge and not be a victim of my situation” [1:p. 149]. Even the macrobiotic life style is assimilated into the healthy-minded approach, with its emphasis on the patient’s active involvement in treatment: when she gives up her macrobiotic diet to return to another regimen of chemotherapy, she commends it for teaching her about the importance of nutrition “in treating and preventing illness,” and then remarks, “... most important, I had taken action against the disease” [1:p. 258].

For many sick persons, a healthy-minded approach seems genuinely helpful, both psychologically and therapeutically. But healthy-mindedness also has the potential for harm and can prove disabling when the course of an illness does not abate or reverse itself, which is what happens here. Radner feels she has done everything possible to create and maintain a positive attitude, and the recurrence of the cancer comes as a bitter betrayal. “Right from the beginning,” she remarks, “I believed that I would get well. I always saw myself surviving...” [1:p. 228]. Moreover, she has “gone public” with this assertion of hopefulness and a positive attitude: as she observes, she had been on the cover of Life magazine as “a symbol of conquering
cancer... a symbol of getting well... a model cancer patient completely active in [her] own therapy.” And now, she concludes, “I felt like a living example that it didn’t work” [1:pp. 228, 231].

Hope is indeed a powerful therapeutic agent, as wise physicians of all kinds have long recognized. But a too aggressively optimistic approach tends to fetishize hope, sometimes with disastrous consequences. Gilda Radner appears to be something of a “hope addict,” willing to accept almost any therapy if it offers her some promise of recovery. Her decision to terminate chemotherapy in favor of a macrobiotic treatment turns on this issue: she perceives the macrobiotic counselor she consults as offering her hope—all I had to do was cook miso soup a certain way...”—in contrast to the oncologist, who “seemed to have no hope for me” [1:p. 238].

Similarly, she abandons the macrobiotic treatment for another, different regimen of chemotherapy (and another oncologist) because she feels it offers her the same sense of promise: “He [the oncologist] was so positive, he was offering me hope” [1:p. 255]. Her fetishization of hope does keep her in treatment, of one kind or another, but it also prevents her from coming to terms with the very real possibility of death. She cannot envisage that her story may have a tragic outcome. From beginning to end Radner is a comedienne, and the humor in this book acts as a poignant and heroic counterpart to the theme of illness and its gradual triumph. But the constant tone of hopefulness becomes ever more shrill as the book and the illness near a conclusion; indeed, Radner’s experience borders on a despair paradoxically generated by her investment in cultivating a positive attitude. The result of this vicious cycle is a desperate need for hope of unrealistic proportions.

THE PHYSICIANS: WHEN THE THERAPEUTIC ALLIANCE FAILS

A second response to her story will focus on Radner’s perception of the medical care she receives. Almost all Radner’s orthodox doctors seem to fail her, in one way or another. Often they do so by mechanical insistence on therapeutic procedures. Thus, on one occasion, when common sense dictates that a particular treatment be discontinued because it isn’t working (she miscarries during an in vitro fertilization program), she is told by her physicians that she has to continue treatments because “this was an experimental procedure and they had to follow their protocol” [1:pp. 35–36]. Research interests here would seem to supersede a primary concern for the patient’s welfare. This incident may explain in part Radner’s animosity, much later, toward a doctor who, when she has a toxic reaction to chemotherapy, insists that she switch to radiation treatments. “We must complete a modality of treatment in cancer therapy” [1:p. 204], he says, a remark that sounds uncomfortably similar to the mechanical explanation given her during the earlier incident. And her description of the difference between what this oncologist says and what she feels he really means suggests a disturbing failure of trust: “He said he could give me chemo and it was treatable, but he implied that I only had a few years” [1:p. 256; italics mine].

The non-verbal messages a physician conveys can be of crucial importance, especially when they contradict what is actually spoken. Such a “subtext” can also determine just how a patient receives and interprets physicians’ verbal statements. For example, at one point Radner describes the radiologist who has read the CAT scan indicating a recurrence of the cancer—a doctor whose facial expression and verbal remarks, taken together, convey a very negative message about both prognosis
and patient: with “a glum look on his face,” he remarks to her, “‘You know, attitude is the most important thing in these cases’” [1:p. 225].

Lastly, there is the oncologist who, she feels, pursues a treatment that he doesn’t really believe will help her: “All I could see in the Connecticut oncologist’s face was that he didn’t believe I would recover. He seemed to have no hope for me and I had no faith in him” [1:p. 238]. Here the medical “gaze,” instead of offering comfort and compassion, only exacerbates the patient’s suffering. This physician fails to understand the particular needs of this particular patient. He does not respond at all to her desperate need for hope; perhaps he is unaware of it. He appears not to know about her dabbling in a macrobiotic life style; probably she didn’t tell him because she felt he would be hostile to the idea.

As this pathography demonstrates, the actions and demeanor of the physician, especially facial expression, language (both what is said and what is not said), and subtleties of behavior, can powerfully influence the patient’s experience when ill, certainly alter response to treatment, and may even affect the course of the illness. Most of the orthodox doctors Radner encounters fail completely in establishing a relationship built on trust, confidence, and mutual respect—what has been called a therapeutic alliance. In many instances, Radner interprets failures in interpersonal skills (of which she gives concrete and convincing examples) as evidence of the physician’s conviction that she is a hopeless case. It might be argued that her physicians, in their reluctance to offer an unsubstantiated hope, are only being true to their understanding of her chances for recovery. If this is so, however, they fail in communicating with directness and compassion that the treatments they advocate are unlikely to reverse her condition. Near the end of the pathography, for example, one medical consultant advises that she use carboplatin with cytoxan, telling her, “‘There’s a ten- to fifteen-percent chance that it will work to retard the cancer, and I won’t say that there aren’t a few cases where it has completely arrested the cancer’” [1:p. 227]. The low percentage, the word “retard” rather than “arrest,” and the negative admission of a few possible successes all suggest that this is clearly an experimental treatment with a poor chance of favorable outcome. Only a desperate patient could commence such a treatment, given this kind of “recommendation.” But Radner is this kind of patient, and she does commence upon this treatment. It is possible that the problems here are interactional; Radner’s physicians, in urging treatments without the hope that gives them meaning, may have unwittingly reinforced her obsessive, near-pathological reliance on hope.

CONCLUSIONS

I began this essay by comparing pathographies like Radner’s to the medical case report, observing that pathographies complement (or perhaps correct) the medical history in their emphasis on the patient, rather than the disease and its treatment. I also observed that the medical history is now undergoing criticism for its virtual omission of the patient—the suffering, feeling human being who should be at its center. Such criticisms of case histories sometimes yield practical suggestions for improvement or reform. William Donnelly, Charles Freer, and David Flood and Rhonda Soricelli all propose not dissimilar solutions to the problem. Donnelly [7] calls for a description of the patient’s understanding of his or her condition to be added at the end of the chart; Freer [3] suggests “anecdotal diagnostic summaries” be included in the problem list; Flood and Soricelli [9:p. 79] would
expand the patient profile to include a narrative sense of the patient's uniqueness and suggest that the computerized history has the potential "for liberating the written history" to record more humanistic responses. Kathryn Hunter [12:p. 174] extends this argument even further, arguing that "As machines take over more of the work of diagnostic reasoning," the case history could be refocused on the important and neglected issues of the place of illness in the life of the patient. Were this change to take place, she concludes, "the diagnostic case history [could] be replaced with a therapeutic one" [12:p. 175].

Such changes and experiments in the form of the medical record are obviously both valuable and legitimate; moreover they may be instrumental in implementing a more patient-centered medicine. What I am suggesting here, though, is that medical humanists and practicing physicians alike might want to look rather carefully at a few of the many pathographies, like Radner's, now in print. For it is this genre in which patient experience is actually given an articulate voice; it is here that patient experience is recorded most fully. These narratives offer a rich source of information about patient experience, and can help us to locate specific issues in the medical enterprise that need understanding and perhaps require change. When we thus focus on the patient, we are likely to discover attitudes and behaviors of direct relevance to the management of that patient's medical condition.

In my commentary on Radner's pathography, I have tried to isolate two elements that directly affect the course of her illness—elements that would never appear in the medical history: her need for a treatment that promises a hopeful outcome, and her perception of her physicians' attitudes about her illness and their expectations as to cure. Of course, there are no easy answers to patient attitudes and expectations that prove disabling, or for the difficulties in the medical encounter indicated here. But pathographies like Radner's are useful because, in restoring both patient and doctor to the story of illness and treatment, they not only guide medicine toward a more humane enterprise—in itself a worthy goal—but also alert us to issues in the medical enterprise that powerfully affect the patient/physician relationship, treatment, and possibly the course of illness. An understanding of the kind of concerns voiced in Radner's pathography will not only make medicine more personalized and more humane; it can also make it more effective.

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