

Virtual Mentor

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IMAGES OF HEALING AND LEARNING

“Sickness Is a Place”: The Foreign Culture of Illness

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“In a sense, sickness is a place...and it’s always a place where there’s no company, where nobody can follow” [1].

The illness experience—time spent in the place of sickness—has been a defining topos of biomedical ethics since that discipline’s birth in the early 1970s. All students of medical ethics and many preclinical medical students are assigned Tolstoy’s *The Death of Ivan Ilych* as a way to begin to understand the torment of a man isolated from his family and friends by his terminal illness.

Long part of the literary canon, in part because it is a manageably short sample of Tolstoy’s writing that showcases his satire of the middle class of his day, this late nineteenth-century (1886) novella was seized upon by the medical ethics community for its close look at existential suffering and the harm wrought by lying to patients about their prognoses. Ilych blames the deception for plunging him into loneliness that “could not have been more complete anywhere—either at the bottom of the sea or under the earth” [2].

In *Imagine a Woman* [3], a late twentieth-century novella by surgeon-writer Richard Selzer, the woman of the title exiles herself to a foreign land to die. If her story is as credible as that of Ivan Ilych, I wondered, would it have anything to say about the difference between the social isolation imposed by a foreign landscape and the psychological isolation induced by illness. Could the former in any way mitigate the latter?

The Internet seemed a likely place to look for a twenty-first-century description of the illness experience. I had followed Leroy Sievers’ radio essays, *My Cancer*, during the 18 months before his death in August 2008 at age 53. Beginning in 2006, his audio diary on national public radio’s *Morning Edition* later became a blog, and all his posts and responses to them by readers are now available on the Internet [4]. Sievers was a journalist who covered wars, genocides, and national disasters for decades. He was employed by *Nightline* for 14 years, during the last 4 of which he was its executive producer.

I have no watertight rationale for selecting these three texts as testing grounds for the hypothesis that sickness is a foreign place and culture. *The Death of Ivan Ilych* seemed an obvious starting place, given its prominence in the medical humanities literature, and the blog, a fitting twenty-first-century destination. *Imagine a Woman*

sprang to mind because I have loved this novella for two decades, and Selzer's romance—for it is one—would have us believe that choosing a place to die can change one's last days for the better; that changing the physical place in which one is sick can change the psychological experience of sickness. We'll just see about that.

At first, the omniscient narrator in *The Death of Ivan Ilych* tells us that what torments Ivan Ilych most is the deception, “the lie which for some reason they all accepted that he was not dying but was simply ill” [5]. “This falsity around him and within him did more than anything else to poison his last days” [6]. What we learn as the last days arrive, however, is that Ivan Ilych's mental suffering and “chief torture” are far worse than and the lying of those around him. It is the lying “within him” that is most excruciating and insufferable. Ilych wonders whether he might not have spent his life as he should have and “the question suddenly occurred to him: ‘What if my whole life has really been wrong’” [7]? And if that is so, he reasons further, “and I am leaving this life with the consciousness that I have lost all that was given to me and it is impossible to rectify it—what then” [7]?

What comes to light finally is his unbearable existential suffering. What if my life has been wrong, false, and I am only discovering it now when it is too late to do anything about it? Indeed, as a public prosecutor and judge, Ilych was conscious of his power to imprison anyone he chose, to ruin anyone he wished to ruin, and, we are told, his success at “these things made his work still more attractive” [8]. Ivan Ilych's several fortnights on the couch in his parlor are spent in a place created by illness in the sense that, absent his sickness, Ilych would not have been removed from the camaraderie of his friends and fellow judges and would not have had the devastating thought that, possibly, his life was wrongly lived. His sickness and isolation, in truth, provide a space in which psychological investigation and disintegration can occur.

It is a long way, physically—and spiritually, one might say—from the button on the back of Ivan Ilych's sofa and the creases in its Moroccan leather at which he stares for weeks to the fragrant acacia grove that surrounds a lakeside *pension* in Veyrier, France, to which an ailing “American woman” escapes. Her story is told in letters to her husband that she has wrapped, addressed, and given to Madame Durand, the concierge, with instructions to post them a month after her death. Madame Gallant—her name is pronounced once by the concierge—has AIDS. Learning that she had contracted the disease from her husband and that the child she was carrying would most likely be affected, Madame Gallant ran off and remained out of touch with her husband for nearly a year. (The inferences that an AIDS diagnosis means imminent death and that her unborn child cannot be spared the disease place the story in the late 1980s or early 1990s.) She has come with “enough money and morphine...to free myself from anxiety and discomfort” [9].

Unlike Ivan Ilych, the woman knows her diagnosis and those around her know she is dying, but there is no discussion of it at the *pension* or in the village. Madame Durand silently provides what is needed to support the woman in her decline; she

serves as midwife when the child is stillborn. The woman documents her failing physical state in her letters: she is losing weight, shedding her skin, her legs feel 50 years older than the rest of her body,

Parts of me are quite raw. Why do they call it shingles? I cannot bear the weight of the sheet on my chest. Once again Madame has provided: a loose, flowing white cotton gown that covers me wrist to ankle with a mantle to raise against the sun [10].

Despite the unrelenting progress toward death, the woman experiences no psychological pain or existential suffering. The lamp light hurts her eyes, causing them to water, but “I weep for no other reason,” she assures Madame Durand [11]. She neither hates her husband nor condemns his secret love. “Despite all,” she writes, “I continue to marvel at love however one locates it” [9]. In the earlier days of her stay, she walked to the village, visited the baker at his brick ovens, and rode up the hill in a truck to the farm of a market woman and her family.

As death approaches, the woman begins to see a diver—“a sweet water Triton”—arise from the lake [12]. They talk, and the Triton tells her to throw a stone into the water when she wants him to come, and he will carry her away. “When I am with him, he is absolutely real,” she writes. “When he has left me, I wonder” [13]. And in the end, she tells the Triton she is ready: “I want to go down” [14].

For Ivan Ilych, death is not a lake and welcoming Triton but a black sack that haunts his dreams.

For three whole days...he struggled in that black sack into which he was being thrust by an invisible, resistless force. He struggled as a man condemned to death struggles in the hands of the executioner, knowing that he cannot save himself...He felt that his agony was due to his being thrust into that black hole and still more to his not being able to get right into it. He was hindered from getting into it by his conviction that his life had been a good one [15].

Is it enough to say simply that Tolstoy wrote of a man tortured by the recognition that he had lived a selfish, mean-spirited life and Selzer of a woman with no regrets? It seems not to be. Can we believe that enough morphine can free one from the anxiety and discomfort of terminal illness? Ivan Ilych had morphine, too. Can knowledge of one’s diagnosis and prognosis, acknowledgement by others that one is dying and deserves respect, and planning for one’s last days—can these be the difference?

Because these are fictions, we can conclude that it is a romantic idea on Selzer’s part that one can elect to slip away from life as into a cool lake in the strong arms of a Triton. It is no less romantic on Tolstoy’s part, however, to have us believe that, if one’s life has been selfish and unexamined, the only way out is being stuffed into a

black bag against one's will. The notion that a bad death will follow a "wrong" life is neither more nor less true, empirically, than the notion that a good death will follow a good life. Both are fictions, romantic fictions.

As the twentieth century progressed, personal, *nonfiction* accounts of suffering from ill health—pathographies—began to propagate. With the Internet and its blogosphere, pathographies now abound. Illness is more thought-provoking than health. It grabs the attention of its victim and screws it to the present. Ivan Ilych's waking moments are dominated by thoughts of "the kidney and the appendix that were not behaving as they ought to" [16]. The American woman's illness fixes her attention on an equally sensuous but more salubrious present.

I have become strangely receptive to the moon, the waterfall, the trees, the bread, the wine, and all the components of this magic village. As my immunity to the germs has dwindled, so has my resistance to these "influences" [17].

With the opportunity for daily blogging, those with illnesses can keep everyone informed of each passing moment—waiting for the next painful diagnostic invasion or the first sickeningly sweet rush of chemical toxins into the system. It behooves a reader to approach pathographies with aesthetic discretion. Many are poor. Leroy Sievers' *My Cancer* is rich.

Sievers acknowledges that, since his diagnosis he lives in a different world [18], a parallel universe. "It looks like the regular world, but it's very, very different. It's populated by other patients with whom you share war stories" [19]. Interesting to me—and more than a side note—is that Christopher Hitchens, international journalism's number one atheist and all-around "bad boy," makes a similar point in his Topic of Cancer essay for *Vanity Fair*. Rescued from his New York hotel by emergency services, "I had the time to wonder," he writes in typical sardonic fashion,

why they needed so many boots and helmets and so much heavy backup equipment, but now that I view the scene in retrospect I see it as a very gentle and firm deportation, taking me from the country of the well across the stark frontier that marks off the land of malady [20].

So far so good for confirming O'Connor's dictum: sickness *is* a place. But at this point, things change for Sievers (if not for Hitchens, who is not the fellow-blogger type of guy). Once others correspond with Sievers, "this whole blog thing" connects him to a defined subculture, those with cancer [21]. He says its members encourage and strengthen him; their e-mails are "stunning in their eloquence, their courage, their determination" [22]. Often he paraphrases from the responses he receives or retells someone's story. After a tough day in August, he asks fellow residents of his cancer world, "What gets each of you through the days? Is it food, a particular treat?"

I do this out of curiosity,” he says, “but quite frankly, I’m sort of running out of tricks myself. I’m looking for some new ones” [23].

The Internet-facilitated interconnectivity among people with like experiences is often ridiculed for the extreme specificity of the links, e.g., a web site for red-haired second children of blended families in which the Irish biological mother is 10 or more years younger than the non-related Italian father. It seems to me now, though, that this sometimes-ridiculed interconnectivity has made possible a subculture in which those with terminal illnesses and diagnoses can escape the loneliness and isolation endured by Ivan Ilych. After sharing some of the correspondence he has received, Sievers says, “so, to all of my friends and to all of you out there who are fighting this disease along with your loved ones, thank you. Like it or not, we’re all in this together” [24].

This is certainly not to say that sharing a virtual “place” and a language with others makes dying any less frightening or more welcome—Sievers *does* say, “like it or not.” It is only to say that perhaps sickness has become a place where there *is* company and people *can* follow, a less isolated place. Would Ivan Ilych be likely to be a blogger were he in Sievers’ shoes? Probably not.

Does the virtual community grant a greater sense of control over one’s life? In a tiny way, maybe sharing loss of control with those who you know will understand counts. Sievers:

I think a lot of you will understand, those who share the journey I’m on. You lose control of so much when you’re diagnosed with cancer. So you try to hold on to as much control as you can, even if it’s just where you go for dinner. In so many ways, large and small, you want to show yourself—if not the world—that you haven’t lost yet. You’re still in charge [25].

So maybe for the large-hearted, sharing sort of twenty-first-century person, sickness is a place, but a place where one is not necessarily alone. But my appreciation for romance forces me to give the last sentence to “the American woman” who had no physicians, no treatment, no ICU, no daily medical assessment of her decline to death. Wonder what that says.

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