

Reflections in Family Practice

Patients On Patienthood: New Voices From The High-Tech Arena

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Every patient needs mouth-to-mouth resuscitation, for talk is the kiss of life.

— Anatole Broyard

Norman Cousins's *Anatomy of an Illness as Perceived by the Patient*¹ appears to have been the harbinger of a spate of new writing about high-tech patienthood by gifted authors who tell about their sicknesses.* They learned their lessons the hard way — in the crucible of experience — and decided to go public, not only for their continued healing but also for benefit of others who might be suffering the same things in silence. They need to tell, warn, instruct, and share what they have learned; but these are not garden-variety self-help books with happy endings.

What is new about this writing is originality and depth, persuasiveness, and lack of deference toward psychologists, social scientists, and physicians — Oliver Sacks and Arthur Kleinman excepted. The authors had the best medical care that money could buy and experienced it in their own unique ways. They are contributing to a new public understanding of what it means to be a patient nowadays. They do not cite the main psychological theories and sociological abstractions that have informed physicians' perspectives, such as psychodynamics and role theory, preferring novelists, critics, and essayists, such as Susan Sontag. They offer no recipes for recovery, no idealized solutions for critical illnesses, no miraculous formulae à la *Love, Medicine, and Miracles* by Bernie Siegal.⁵

Submitted 30 June 1992.
From Birmingham, AL.

*This essay draws mainly on three new books: the first by Arthur Frank, *At the Will of the Body*,² the second by Anatole Broyard, *Intoxicated by My Illness*,³ and the third by William Styron, *Darkness Visible: A Memoir of Madness*.⁴ I have used Frank's story sequence as my framework and superimposed Broyard's remarkably perspicacious and clever chapter, "The Patient Examines the Doctor," as counterpoint. Styron's account is a background theme.

High-tech medicine has now been around long enough for literate patients to have discovered its peculiar social and cultural characteristics. They have complaints against the medical system and the behavior of its agents — both in the United States and Canada — but this writing does not have its primary focus on grievance, revenge, or reform; and the authors show no intent to abandon medical care. They seem to accept, ruefully, that medical care is flawed and holds little promise for reforming itself; therefore, patients must do for themselves what the system omits or fouls. Medicine is a hard but necessary reality; it would be nice if it were different and more humane, but there is no time to wait for medicine to change. Patients must learn to cope while remaining patients; critical illnesses must be lived, step by dogged step; and winning is not always possible.

The Authors

Arthur Frank, a medical sociologist in Calgary, had two life-threatening sicknesses within 15 months when he was 39 and 40 years old. First was an episode of ventricular tachycardia, presumably from viral myocarditis; next was cancer of a testicle with metastatic abdominal lymphadenopathy. He recovered from both, but in the process he and his wife, Cathie, discovered how much their lives were changed and what they needed to survive and assimilate the changes.

Anatole Broyard, a long-time editor, critic, and essayist for *The New York Times*, died of cancer of the prostate, and his book was published posthumously by his wife. It is a gem of erudition and wit and has a playful quality despite the seriousness of its topic. His chapter "The Patient Examines the Doctor" deserves a permanent place in the literature about the physician-patient relationship.

William Styron, novelist and playwright, recovered from a severe major depressive disorder after 7 weeks in a hospital. His style strikes me as

a bit ponderous, but it cuts to the bone his personal experience with a suicidal depression that would not yield to drug treatment. He shows how pervasively depression insinuates itself into the details of one's life and disguises its presence to patient and physician so that a heroic effort is required to seek treatment. He credits the hospitalization itself with saving his life, apart from any specific treatment.

It is possible that these patients would have overmatched any physician, yet their diseases were not extraordinary by modern standards. What they wanted, but did not get from their doctors, was less esoteric than ordinary; the failures were low-tech failures of conversation, imagination, and understanding.

Frank's account is written simply, intensely, and with a deep wish to communicate. He acknowledges that the writing is a part of his recovery and demonstrates thereby his new-found freedom to speak directly and honestly, to focus his energy, to abjure hypocrisy, and to grasp his life despite its vulnerabilities and the ultimate certainty of death. The form of his book is conversations with his younger self as a strategy for uniting his past, present, and future, but he cannot avoid also conversing directly with his readers, who in one way or another are destined to face the same dilemmas. In this respect the book is not just a literary exercise, it is also a passionate tract.

The Discovery of Disease

Patienthood begins with the discovery that one has a disease, a process that on the surface seems like it ought to be straightforward in high-tech medicine. One has a symptom, consults a physician, gets examined and tested, and receives an accurate diagnosis. In Frank's case, however, it was not so simple, and one suspects that the diagnostic process miscarries far too often, leaving residues of regret and recrimination for both patients and physicians. Even when diagnosis is easy technically, reporting and receiving it are highly charged emotionally, and physicians are apt to underestimate its impact.

In Frank's first instance, he collapsed while running, lost consciousness for a brief time, then recovered and felt well enough to delay seeing his physician until the next day. By that time his examination was normal, except for a precautionary electrocardiogram, which inexplicably was not re-

ported to him for a week. It showed a "heart attack." Then followed a series of cardiac investigations, culminating 6 months later with a normal coronary angiogram — and great relief.

At first, he was too willing to underestimate the signals from his body and to accept the physician's reassurance that nothing serious was wrong. They colluded with each other not to seek the deeper truth. He writes:

My mind wanted to forget it. My body said no. Something was wrong; something had changed, seriously. When I saw my family physician, he went along with my mind's version^{p 9}

After a diagnosis of heart trouble was made, he resented the physician's polite but cool and detached attempt to objectify the problem as an "it" that could be fixed. He said about this conversation:

Our talk was classier than most of the conversations I have with the mechanic who fixes my car, but only because my doctor and I were being vague. He was not as specific as my mechanic usually is No one should be asked to detach his mind from his body and then talk about this body as a thing, out there.^{p10,11}

Professionalism became a barrier to the sort of communication he needed most. He wanted recognition of what had happened to him, but he could not even phrase the questions. News that one has had a heart attack changes the way one lives in one's body. Having come close to dying suddenly creates a fear that it will happen again, and that one could die in one's sleep. His doctor should have found a way to let him know he recognized that. His advice to readers:

Recognize that more is happening to you than you can discuss with most physicians in most medical settings. To talk about illness you must go elsewhere.^{p15}

Broyard received prompter diagnosis, but the effect of being told was nonetheless jarring. He observed:

You don't really know that you're ill until the doctor tells you so . . . it was like an immense electric shock All my old trivial selves fell away and I was reduced to essence. I began to look around me with new eyes, and the first thing I looked at was my doctor.^{p37,38}

Politeness and objectification also came in for comment by Broyard. His first doctor did not impress him as intense or willful enough to prevail over something powerful and demonic like illness.

He was bland, hearty, and vague, polite where politeness was irrelevant. I felt he would be polite even to my illness . . . I didn't like the way he spoke: it struck me as deliberately deliberate, the speech of a man fixed in a pose, playing doctor . . .^{p36}

What turned me against him was what I saw as a lack of style or magic. I realized I wanted my doctor to have magic as well as medical ability. It was like having a *lucky* doctor . . .^{p39} I thought, I can't die with this man.^{p38}

In the second illness, Frank had to consult four physicians to discover the cancerous cause of testicular soreness and back pain. His family physician first treated him for a chlamydial infection; an emergency physician diagnosed chronic constipation; a sports medicine internist discovered abdominal masses, suspected cancer, and arranged for sonographic examination; and it was the sonographer who gave him the dread news.

The cancer news induced in him a state he calls incoherence — coming unglued. His future “disappeared,” and he felt as if he were “walking through a nightmare.” His back pain isolated him and disrupted the routines of daily living. He did not even try to talk with a physician about his altered self-consciousness and was finally able to restore coherence by experiencing a scene of beauty, writing a haiku about it, and caring for his wife's sleep by choosing not to awaken her when he was in pain. Externalizing his caring restored his capacity to care for himself.

Madness, irrationality, and absurdity are Broyard's equivalent to Frank's incoherence. When his doctor told him about cancer in the prostate that had spread to lymph nodes and probably bone, it induced in him “the panic inherent in creation” and “the suction of infinity.”

To be sick is already to be disordered in your mind as well . . . I feel that my absurdity is part of myself. I have to accommodate it. I wanted a doctor who would answer to my absurdity and triumph over it.^{p39}

As much as he desired to do so, he could not sit down and talk with his urologist about it.

I would like to have a meditation, a rumination, a lucubration, a bombination, about the prostate. I can't do it. I'm forced to stop people on the street and talk to them about it.^{p52,53}

Medical astuteness does not insure that doctors understand that all cures are partly talking cures. The doctor ought to talk and also “bleed the patient of talk.”

Every patient needs mouth-to-mouth resuscitation, for talk is the kiss of life.^{p53}

Discovering that one has a life-threatening disease is a fragile time. It has a global impact on work, leisure, plans for the future, friends and colleagues, and most of all on intimate relationships. One cannot turn one's body over to experts for repair while keeping one's mind and life in neutral. Disease turns into illness, the total experience of being sick, and every loss must be mourned.

Middle Issues in Coping

Medical personnel, family, and friends want patients to pass through mourning quickly, because it both slows treatment and reminds others of their mortality. “Professionals,” Frank asserts, “talk too much about adjustment” and are too eager for “bouncing back.” But mourning has its own time table and is necessary for finding a life on the other side of loss.

Others prefer that sick persons maintain an attitude of surface cheerfulness. Broyard's friends flattered him by saying he was courageous or gallant, but he expected his doctor to know better.

I don't ask him to love me . . .^{p43}

[What the sick] wants most . . . is not love but an appreciative critical grasp of his situation . . . “empathetic witnessing.”^{p44}

Frank is put off by “stage theories” of adaptation to sickness or death, such as Kubler-Ross's. They are generalities about what is “normal” or expected, and they allow professionals the illusion of understanding without having to engage the patient's particularities.

The last thing an ill person needs is to be treated as “only going through the panic stage.”^{p46}

Care giving, whether by professionals or amateurs, must be a symmetrical relationship of listening to and understanding the patient's changing needs. One cannot expect a patient to know or say what those needs are from day to day.

Being critically ill means never being able to keep up with your own needs.^{P47}

Treatment and providing services are not the same as care giving. Frank accepts that medical staffs might not have the time to become care givers, but he also suspects that they lack the inclination. Moreover, family members can be seduced into substituting services for the harder work of witnessing and sharing the illness.

Undergoing treatment entails continual negotiations for balance between submission of one's body and control of one's life. Frank experienced submission as ceding the territory of his body to anonymous experts who "colonized" it as their proprietary right. He imagined the central venous line as a flag of conquest. Physicians assume that they are the actors, the stars, in the drama of treatment, and the patient's job is to be good-natured and obedient as a matter of good manners and moral duty. Frank asserts that control, or at least management, becomes a medical ideal; patients who ask too many questions, who seem skeptical or hesitant, will meet resistance and challenge. The deal that seems to appeal most to medical experts is, "Let me worry about the disease; you worry about other things." And if the doctor is an older man and the patient a woman — like Gilda Radner — the clincher is, "I'm going to treat you like my own daughter."

When a nurse came to assess the Franks' "psychosocial" needs, there was no privacy, only the illusion of privacy provided by a curtain pulled around the bed. They were unable to respond — except by lying — because the circumstances precluded openness. Anyone who seems to offer support "must not only have real support to offer but must . . . convince the ill person that this support is there." Admitting that one has problems increases vulnerability, and patients learn that they must make the best deals they can with the professionals, even if that means pretending to be all right.

There are asymmetric relationships of intimacy between medical staff and patients; the patient's

life is an open book (chart), but professionals share little of themselves. Moreover, they can choose what and when to share but rarely can match the patient's emotional intensity. Frank mentioned a resident who said he was interested in his "social history," then satisfied that curiosity with a single question about Frank's job. It was infuriating that the resident thought that was enough to recognize a patient as a "social" being.

Proust, according to Broyard, said that "his doctor did not take into account that he had read Shakespeare." In addition to bone scans, Broyard wanted the doctor to scan him, "to grope for my spirit as well as my prostate." He imagined that the doctor might actually enjoy him and that their relationship could be beautiful. He wanted to become a good story for the doctor and give something back to their relationship. He wanted the doctor to know that, in some ways, he is superior, "that he is my patient also and I have my diagnosis of him."

There should be a place where our respective superiorities could meet and frolic together.^{P45}

On one occasion Frank forced an anesthesiologist to shake hands with him at the termination of a preoperative visit, during which the doctor spoke without looking directly at him. What Frank wanted was recognition of what he was living through. He felt that he was constantly being reminded of how little he knew and how much the doctor knew and how much more he knew than he said. The reality was that the more critical his diagnosis became, the more reluctant physicians were to talk with him.

Failure to make eye contact is distressing to patients. Broyard recalled a doctor who reacted to eye contact "as though I had touched him in the genitals."^{P50} He thought that clinical work would be more gratifying if doctors and patients gaze at each other. Avoidance probably contributes to doctors' feelings of harassment and testifies to their own fear of failing.

Why bother with sick people, why try to save them, if they're not worth acknowledging?^{P50}

Despite the presumed power of treatment, recovery depends on the "wonder" of the body's responses. Not only can the body not be controlled,

but ways must be found to test its resilience in the face of illness. Frank discovered wonder by exercising and once by walking in a drenching rain. He was amazed by what his body could still do and began to draw strength from it instead of resenting it.

Frank will have no truck with images of the body at war with itself or with disease as a personified enemy. Also, he rejects all notions, no matter how far-fetched, that the sick person should feel guilty for being sick. He is especially bitter about theories of "cancer personalities" and finds it better to believe that cancer just happens. To locate the trouble within the sick person, theologically, psychologically, or behaviorally, means that the person has to change and everything else remains the same.

The fault and the fear are safely contained, locked up inside the cancer patient. Cigarette companies stay in business, polluters can pollute, advertisers can glorify sunbathing, and those who enjoy good health can believe that they earned it. Only the ill are left to feel guilty.^{p113}

Would-be comforters, as in the case of Job, too often turn out to be accusers. In rejecting self-victimization, however, Frank does not try to evade personal responsibility for coping with the illness. This entails a struggle but not a fight.

There was no fight, only the possibility of change Thinking of tumors as enemies and the body as a battlefield is not a gentle attitude towards oneself, and ill persons have only enough energy for gentleness.^{p85}

For him, the struggle was in keeping body and mind together and replacing will with faith in their unity. Although he uses some religious language and Biblical references to Jacob and Job, one does not get the impression that he drew strength from any particular religious tradition. He also used the poetry of Paul Simon, "The Boy in the Bubble," and visually imagined his white blood cells standing guard like Greek soldiers, silhouetted on mountain cliffs. The Battle of Marathon reminded him of running a marathon, an experience during which one must coddle one's body rather than fight it. He warns readers to choose their personal stories and mythologies carefully; they are both powerful and dangerous.

In the end there is chance in getting sick and luck in getting well. Recovery cannot be the only acceptable goal.

I am not powerful enough to feel either guilty for getting sick or proud of getting well. I can only take what happens to me and continue to look for possibilities of how to live.^{p88}

Broyard disagrees with Frank on this point. He wants to own his illness as a way of personalizing it and rescuing it from science. He'd much rather think that he brought it on himself than that it was a mere accident of nature. He imagines playful pleasure if his urologist could say, "You know, you've worked this prostate of yours pretty hard. It looks like a worn-out baseball."^{p47}

If the patient can feel that he has *earned* his illness — that his sickness represents the grand decadence that follows a great flowering — he may look upon the ruin of his body as tourists look upon the great ruins of antiquity.^{p 48}

While these comments are tongue-in-cheek, the feeling of responsibility for one's illness varies among patients. Styron vacillates between seeing the origin of depression as unfathomably complicated and believing its roots lie in his childhood. He is psychologically oriented, and his self-esteem is not threatened by psychological explanations. Causality is not destructively linked to moral culpability, as it seems to be for Frank. Both agree that seeking treatment should not be influenced by notions of blame.

Afterwards

Recovering from a disease is not the same as recovering from the illness. There are altered relationships with family and friends and the need to re-engage oneself in one's work. Some friends will fall away and others will become closer. There is pressure to make up for lost time at work and to become productive again. Most of all there is need to value the illness and to develop a sense of gratitude for being alive that Frank calls "gravy."

Living as a member of the "remission society" is a new phenomenon in human experience, made possible by high-tech medicine. Frank imagines it to be like Jonah.

How strange and wonderful the world must have looked to Jonah Could he preserve the poignancy of that first moment, after three days in the slime and the stink, when he saw the light and land and water, and knew the face of God?¹⁴²

We need, Frank thinks, to develop some rituals and ceremonies for illness, to celebrate the steps along the way. He remembers vividly seeing his coronary arteriogram while it was being performed and feeling reborn. There was a sense of adventure during chemotherapy, despite its uncomfortable side effects, and overwhelming relief for both himself and Cathie when the "central line" was removed, marking the end of chemotherapy. A nurse acknowledged their tears by saying exactly the right thing: "I guess this must be kind of a big moment for you." Perhaps there also should be some ceremonies for care givers, who have not only had to manage their own lives but also remain faithful to the patient.

Things do not return to "normal" after an illness. There is uncertainty and fear that can diminish a person, but life in the remission society might be a truer picture of the way things really are for all of us.

Comment

Admittedly these writings are one-sided; one can only guess what the authors' physicians thought and felt when reading these books. Nevertheless, it is hard not to observe that physicians appear to be learning the wrong lessons from the changed conditions of modern practice — more malprac-

tice litigation, increased patient autonomy, marketplace competition, and less physician paternalism. Despite the demands for more and better services, increased accountability, and deeper understanding, physicians retreat into defensive medicine, professionalism, arcane jargon, and homogenized protocols of diagnosis and treatment. The times call for openness, imagination, mutuality, flexibility, and personal attentiveness — not retraction into a protective shell of expertise.

Physicians seem to have misunderstood the message, the invitation, to close the gap of physician-patient communication. Patients are saying we need you, come closer, don't be afraid, get to know me and let me know you; but physicians fail to look them in the eye; they quote statistics, remain polite and trivial, and speak only of disease as an objective reality. The paradox is that the increased risks of practice can be reduced only by daring to take the risks of intimacy.

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