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MAKING THE ROUNDS

IN HEALTH,
FAITH,
& ETHICS

VOLUME 1, NUMBER 6

PUBLISHED SEMIMONTHLY BY THE PARK RIDGE CENTER

NOVEMBER 20, 1995

The Red Ribbon

Linda E. Clarke

Time changes when a person you love is sick—it narrows at the edges and lengthens in the middle. The things that were once part of your life become shadows dancing just out of sight like the memory of a good movie or a fine meal. People (you think) get bored with you, tired of your focus on the sick person you love, anxious for you to get on with things. So little by little you fall out of the loop and live on a ribbon stretched taut between your heart and the one who is sick. The ribbon between my heart and my father is red.

My ribbon reached from Toronto to Montreal, and time was a passage—Highway 401 to Montreal every second Friday and back again on Sunday. The journey was marked by McDonald's, Tim Horton's doughnut shops, the Quebec border, and a sure knowledge of the cleanest washrooms in that six-hour ribbon. The passage was marked by cassette tapes and the change of seasons: hot, shimmering summer, cool, bright autumn, biting cold winter.

Patients in my father's hospital were permitted to eat their meals in the cafeteria only if a family member or friend accompanied them. Otherwise they perched on the edge of their beds or in wheelchairs and ate their meals off of orange or pale blue melamine trays, facing the walls or facing each other.

The sounds of clinking dinnerware, sliding trays, and muffled voices in rare snatches of conversation wash over me as I step off the wide-doored elevator onto the fourth floor this early evening. Trolleys with half-empty trays and remnants of the evening meal stand abandoned by the nurses' station, smelling vaguely of fish and canned peas. The weeping woman is sitting in her usual place against the wall just outside my father's room. Wearing a huge white sail of a bib, she rocks and sobs as a young nurse valiantly tries to feed her. I walk by her, trying not to notice her, working to avoid eye contact. I pass within inches of her hand; I pretend to be intent on room numbers and wall calendars. I tell myself there's just so much that I can be expected to do, just so much emotion I have to spare. I'm here to eat dinner with my Dad.

Linda E. Clarke is an educator in the Clinical Ethics Service of three Toronto-area hospitals in Ontario, Canada: St. Michael's Hospital, St. Joseph's Health Centre, and Providence Centre.

Reflection

The ribbon between my heart and my father is red, the color of blood.

Dad is up in his wheelchair, waiting for me. He smiles and squeezes my hand. "Hungry," he says, both a statement and a question.

From the other side of the room his roommate waves at me, hollers at me above the Walkman in his ears, "I'm getting out of here in a week, ya know. Just a week!" I smile and nod. The man's

health troubles me. After three coronaries and a massive stroke, he still looks as if he just stepped off the golf course. Tonight his straight back and clear speech upset me.

As I push Dad's wheelchair toward the door, I notice the *Globe and Mail* on the bedside table, folded neatly. Dad is teaching himself to read again; it takes him half a day to pick out a word

that he recognizes. Nothing to sneeze at for a man who couldn't remember his name just four short months ago. This night that newspaper taunts me with childhood memories of Dad in his green armchair snapping the paper sharply as he turned the page, classical music on the record player and me with my homework spread on the living room floor at his feet.

The ribbon between my heart and my father is red, the color of anger.

I maneuver the chair through the door toward the elevator. Dad waves to the weeping woman and nods to the nurse still trying to feed her. At the head of the hallway a young man with a red tartan blanket over his knees lifts his hand and waves to Dad. Dad waves back and smiles inside every door as we pass by.

The cafeteria is on the main floor in a back corner of the building. It is small and ugly but for the two walls of windows overlooking the fields, now painted in the autumn colors of early evening. The fading sun makes the trees black against a reddish light; a strip of blue hovers over the horizon. Sumac and stubborn maples splash red. It is a beautiful sight. Dad and I sit by the window and watch together.

The menu is far from appealing tonight: fish sticks, boiled chicken, boiled potatoes, rice, salad, cookies, and tea. Leaving Dad, I stand in line with an orange tray behind three white coats. One, I think, is Dad's doctor, but she doesn't seem to recognize us. I buy

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Managing medicine

"Changes in health care now focus almost exclusively on the system of care, not on care itself. The central importance of the patient is lost and the importance of the patient-physician relationship usually is not considered. . . . As the system moves toward a consumer model, the patient becomes less a person and more an entity, the physician more a manager and less a doctor. And the physician's vision of the patient becomes blurry as layers of other concerns are set between the patient and physician."

(*Academic Medicine*, September 1995)

How things have—and haven't—changed

Eighty-one-year-old Francis D. Moore, Moseley Professor of Surgery Emeritus at Harvard, reflects on his long career as a surgeon and the issue of prolonging life or permitting life to end:

"Doctors of our generation are not newcomers to this question. Going back to my internship days, I can remember many patients in pain, sometimes in coma or delirious, with late, hopeless cancer. For many of them we wrote an order for heavy medication to be given regularly by the nurses. Morphine by the clock. We were assisting with a softer exit from this world. Nurses helped willingly. This was not talked about openly and little was written about it. It was essential, not controversial."

(Francis D. Moore, *A Miracle and a Privilege*, Joseph Henry Press, 1995)

Abortion and the language of right and wrong

Noting the pro-choice movement's "abandonment of what Americans have always, and rightly, demanded of their movements—an ethical core—and its reliance instead on a political rhetoric in which the fetus means nothing," Naomi Wolf argues for a radical shift in the pro-choice movement's rhetoric and consciousness about abortion. "Clinging to a rhetoric about abortion in which there is no life and no death," she points out, mem-

bers of the movement entangle their beliefs "in a series of self-delusions, fibs and evasions" and risk losing their souls. To avoid a cheapened view of human life, Wolf maintains that pro-choice individuals "need to contextualize the fight to defend abortion rights within a moral framework that admits that the death of a fetus is a real death; that there are degrees of culpability, judgment and responsibility involved in the decision to abort a pregnancy; that the best understanding of feminism involves holding women as well as men to the responsibilities that are inseparable from their rights; and that we need to be strong enough to acknowledge that this country's high rate of abortion—which ends more than a quarter of all pregnancies—can only be rightly understood as what Dr. Henry Foster was brave enough to call it: 'a failure.'"

(*New Republic*, 16 October 1995)

The "personal" and the "political," ethically speaking

William H. Willimon offers a critique that could be germane to many discussions of patient and professional "autonomy" in health care. "There is no such animal as the 'private' self, the self prior to or somehow utterly detached from a public. Our language, symbols, and reason are socially, that is, publically, constructed. People . . . don't just have 'personal' problems, they have 'political,' that is, power, problems related not to some failure of psychological adjustment but to the way power is used and abused in this society.

"There is, therefore, no 'private' ethics, for no ethic can be separated from political, public questions like, What sort of world do we live in? or Who benefits from the present power arrangements? No matter how much we reassure ourselves that our private actions are 'my business and nobody else's,' all action contributes to or detracts from the public good."

(*Theology Today*, October 1995)

Which Second Coming?

Commenting in a *New York Times* editorial on anticipated cuts in Medicare and Medicaid,

Melvin Konner, of Physicians for a National Health Program, waxes biblical and theological. Noting that a presidential candidate has referred to the Second Coming of Christ, Konner asks, "Which Second Coming? The one brought on by Armageddon, or the one that many Christians believe grows gradually in the world through the imitation of Jesus Christ?"

Konner continues, "Deep in the Judeo-Christian tradition are such sentiments as 'Do justice to the poor and fatherless; deal righteously with the afflicted and destitute.' A modern politician who transfers wealth from the suffering to the comfortable and cuts off poor people's access to decent medical care might wonder how he would stand in a Second Coming."

(*New York Times*, 13 October 1995)

Diagnosis and time

Philosopher S. Kay Toombs was diagnosed with multiple sclerosis in 1973. In *Humane Medicine* she offers "reflections on meaning and wholeness" and "the ways in which we experience our bodies differently in health and illness." She observes, "A most important aspect of illness is a change in the significance of time. . . . With the prospect of increasing debility, the future assumes an inherently problematic and threatening character. So pervasive is this threat that the future engulfs the present. An uncertain or dire prognosis may cause the sick person to start living as if already incapacitated or as if death is imminent." She cites a University of Western Ontario survey that indicated that "simply receiving a diagnosis of MS was equivalent to moderate disability, regardless of the actual degree of physical impairment."

In a culture that values the present largely for its contribution to the future, Toombs concludes that "if healing is to be achieved, patients have to learn to live fully in the present moment."

(*Humane Medicine*, August 1995)

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Making the Rounds in Health, Faith, and Ethics (ISSN #1082-1015) is published semimonthly, except monthly in July and August, for \$29.95 per year (\$40.00 for institutions) by the Park Ridge Center for the Study of Health, Faith, and Ethics, 211 E. Ontario, Suite 800, Chicago, Illinois 60611. Application to mail at second class is pending in Chicago, Illinois, and additional entry. POSTMASTER: Send address changes to *Making the Rounds*, The Park Ridge Center, 211 E. Ontario, Suite 800, Chicago, Illinois 60611, attention subscription fulfillment. © 1995 The Park Ridge Center, an affiliate of Advocate Health Care. Printed on recycled paper. TO SUBSCRIBE: send a check for \$29.95 per subscription (\$40.00 for institutions) per year (payable to the Park Ridge Center; please add \$20.00 per year for non-U.S. subscriptions) to the above address or call 312/266-2222 to order with Visa or MasterCard. Back issues are available for \$2.00 each (includes postage and handling).

The Quest for Meaning in Illness

Ron Hamel

Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), 213 pp.

Day after day on morning rounds in teaching hospitals, resident physicians tell the stories of their patients. These stories usually consist in a brief account of the patient's past medical history, the reason for admission and the history of the present illness, current medical problems, vital signs and lab numbers, and a plan of treatment. The patient's medical record contains more of the same, along with consent forms, doctors' orders, nursing notes, and dictated consultation reports from subspecialists. For all practical purposes, this is the "patient's story," perhaps with a bit of social history thrown in, told over and over again by those caring for the patient.

Does the story change when it is told from the patient's perspective? Sometimes it does. But often it does not: the patient's own story is simply a version of the physician's story about the patient. The patient's story of illness is defined by the medical narrative, though it may be amplified somewhat by additional information about the patient's life as it bears upon the current illness. Frequently missing is the patient's own voice expressing what it is that the illness means, how it has affected her and her life, and how she is responding to it. Consequently, much of what the patient is experiencing, beyond physical symptoms but just as much a part of the illness, is not being expressed.

In *The Wounded Storyteller*, Arthur Frank confronts this problem. He seeks here to shift illness narratives from stories *about* the body (as in the medical record) to stories told *through* a diseased or wounded body. What does this mean, and how does it occur? In the first place, Frank believes that the experience of illness has changed in recent times, that more people who are ill are attempting to reclaim their voice in the illness experience, to reclaim the capacity to tell their own story, to make *their* story of their illness the primary one. These individuals want their suffering to be recognized in its uniqueness and not simply as another case of cancer or heart disease or whatever. They want to speak for themselves rather than be spoken for. This very process, according to Frank, involves taking responsibility for one's illness and the meaning of that illness in one's life. That responsibility is frequently expressed in telling stories for the sake of both self and others. This activity is a major shift from the traditional "sick role" in which the patient surrenders himself to the care of the physician and responsibility consists only in complying with the physician's orders in order to get well. Exercising responsibility in illness by telling one's story of illness is ultimately for Frank a moral action. Storytelling gives rise to ethics.

Ron Hamel is director of the Department of Clinical Ethics, Lutheran General Hospital—Advocate, Park Ridge, Illinois.

People tell their stories of illness, according to Frank, for the quite practical purpose of letting other people know what is happening with them, but also, and more important, to repair the damage that illness has done to their sense of themselves and the coherence of their lives. During illness, especially serious illness, people often lose the map that had previously guided them and their lives. They experience, in addition to illness, "narrative wreckage." In telling stories of illness, however, the ill person is able to redraw life's map and seek new directions and destinations. He is able to remake himself as well as his future. What is at stake here, then, is how one responds to illness—not all responses are equally desirable. Here Frank introduces a "normative element" that enables him to speak of his book as a work in "narrative ethics."

Employing the language of a sociology of the body, Frank identifies four "body types" that reflect different ways in which individuals respond to their illnesses. More precisely, these types reflect choices that body-selves subsequently act upon. These

choices cluster around four "problems" that all bodies, but particularly those experiencing illness, must deal with—how they cope with contingency in their lives (issues of control), how they relate to their own bodies, how they deal

Storytelling gives rise to ethics.

with desire, and how they relate to others. Responses to these problems (which fall along a continuum for each) give rise to the disciplined body, the mirroring body, the dominating body, and, finally, the communicative body. Frank holds up the communicative body as normative, as an ideal to be realized.

The communicative body deals successfully with each of the problems noted above, but perhaps what most distinguishes it is its orientation toward others. Not only does it, in its illness, continue to constitute its humanity in relationships to others but it makes others the object of its desire. It wants and needs to relieve the suffering of others; it seeks to exist at least in part for the other. The stories of illness that the communicative body renders to others are meant to assist them in their own suffering and their own attempt to repair their narrative wreckage. Hence the ethical task is twofold: the ill person is choosing both to create a new self and a new future for that self and at the same time to help others in the same task.

All body types are not equal for Frank; nor are all narratives. Frank identifies three narratives that are shaped by the ways in which the tellers deal with the four "body-problems." The first, and the most common, is the restitution narrative. The culturally preferred narrative, it is reinforced by the very practice of medicine. The plot line is essentially restoration to good health: the good health of yesterday was interrupted by illness today but will be restored tomorrow. Here the ill person's responsibility is limited to doing what must be done to get well. In the second type of

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Does Managed Care Disable Rehabilitation Therapy?

HEALTH CARE INCLUDES MORE THAN HEROIC ATTEMPTS to rescue critically ill patients from death by means of dazzling high technology or drugs and advice aimed at helping people “get better” after an illness or injury. Within the universe of health care, rehabilitation medicine is a world of its own. There, caring and teaching, trying to restore and maximize a person’s quality of life and ability to function are more central. The labors are quieter, and achieving results takes longer. Miracles occur as often or more often than they do in acute-care settings, but they are more low-key.

The world of rehab has been a small and outer planet. Society has allocated most of its health care resources to hospitals and their armies battling death and seeking cures; the disabled, the chronically ill, and the terminally ill have been left with less recognition and fewer resources. And managed care, with its focus on measurable and standardized outcomes, on “critical paths” with timeliness and benchmarks to measure progress, and on saving money by reducing reimbursements for services, has intensified the ethical pressures and challenges faced by rehabilitation professionals.

A team of professionals in rehabilitation medicine at a small community teaching hospital in Chicago, during a series of discussion sessions, recently voiced some of their ethical concerns. A physical therapist, speech therapist, and manager of a comprehensive rehabilitation therapy clinic described their struggles in a health care environment increasingly driven by economics.

“I feel more like a mechanic than a therapist nowadays.

**It seems that all I can do is ‘assess the patient’
and watch him or her leave the unit for
a less expensive setting.”**

I feel more like a mechanic than a therapist nowadays. Years ago, my patients and I grew to know and love each other. We became friends. You cannot imagine the sorrow at meeting a child after an accident who could no longer move—or the joy, long months later, of watching that child cross a room to give his parents a hug. Now it seems that all I can do is “assess the patient” and watch him or her leave the unit for a less expensive setting, because the patient’s insurance won’t provide for the therapy he needs. Sometimes I feel that I must either resign myself to shortchanging my patients or look for another line of work. (*physical therapist*)

I remember an elderly lady, Sarah, whom I met eight weeks after she’d had a stroke. We had just begun making real progress with her swallowing and her speaking when word came down that her insurance would not cover any more treatments. I tried to advocate for her, but my arguments weren’t enough. I even tried “white lies,” fudging a bit on the documentation to try to extend her benefits—and lost sleep because of a guilty conscience. I worried that she would fall at home, that she was leaving too soon. Sure enough, a week later she was back in the hospital with a broken hip. How does that make sense, ethically or economically? (*speech therapist*)

I work at a faith-based hospital, with a strong traditional commitment to taking care of the poor. Our chief competitor, a rehab unit at an investor-owned, for-profit hospital, is dumping more and more patients who can’t pay for treatments or whose progress can’t be documented easily and who might make their statistics look bad to managed-care payers. Our unit is the only hope for some of these patients, and we are getting more than our share of them. We are using lower-paid staff, teaching patients and families as much as we can, and “exercising our creativity” until we feel like screaming. And we are losing money. Is it fair that our mission to be there for the most vulnerable patients is moving us to the brink of financial insolvency? (*clinic manager*)

Should therapists simply accommodate themselves to the ever-narrowing limits of reimbursable care allowed by money-oriented managed-care organizations? Should they shortchange their patients’ welfare, accepting high levels of risk to their patients’ safety, for the sake of staying in business? Should they “game the system,” practicing “creative documentation” in order to help their patients? Do they stick to their ethical commitments, abjuring the cutthroat practices (for example, “cherry-picking”) of other clinics, even when those commitments threaten their own survival? Should they “hang in there,” hoping that conditions will improve? What can we say to them?

Giles Scofield, J.D.*Pace University School of Law, White Plains, N.Y.*

REHABILITATION MEDICINE HAS MORE TO OFFER traditional medicine, mainstream ethics, and a society on the verge of a health care crisis, than vice versa. With its holistic approach to the patient, its ideal of interdisciplinary teamwork, and its emphasis on using informed consent to educate patients, rehabilitation medicine routinely treats patients in ways that are still regarded as extraordinary in acute-care medicine. Because of the need to integrate quality-of-life considerations into medical decision making, rehabilitation medicine forthrightly addresses issues regarded as taboo in many other circles. Finally, because it views its mission as adding life to years, and not just years to life, rehabilitation medicine concerns itself with issues that matter dearly to persons with disabilities.

Notwithstanding what rehabilitation medicine has to offer (and perhaps precisely because of what it has to offer), it remains the distant, underappreciated cousin of high-tech medicine. Its inferior status relative to acute medicine creates the crunch that many in the rehab field are currently experiencing. The insurance industry, concerned with cost-effectiveness and devoted to definite outcomes, understandably views much of what goes on in rehab as a waste of time

Rehabilitation medicine has more to offer traditional medicine than vice versa.

and money. No matter that rehab takes time or that recovery from a catastrophic injury is an incremental process; when measured against the template that insurers use to judge results in the acute-care setting, rehab inevitably comes up short. The legitimate expectations and values of rehabilitation medicine are illegitimate in the eyes of traditional medicine, payers, and even ethicists.

Because rehab is being judged according to standards that it cannot realistically be expected to meet, the pressure to survive and the anxiety about performance are destined to have a detrimental impact on rehab. It is fair to expect that misconceived treatment expectations will drive out committed health care professionals. The quotations offered above (p. 4) are commonplace among rehab workers and are routinely followed by statements that some career change lies ahead. Sadly, because rehab professionals are accustomed to working within limits, many are likely to see the limits placed on health care as one more handicap to be overcome.

In fact, rehabilitation medicine holds the promise of rehabilitating medicine. After all, if the rest of us are having a tough time dealing with quality-of-life issues, if society is being pressed to meet the needs of individuals who are chronically ill or disabled, if physicians are looking for ways to connect better with patients, and if patients are looking for medicine that uses technology for them and not on them, rehab has much to offer.

John Wax, L.C.S.W., M.S.W.*Ethics consultant, Los Altos, Calif.*

REHAB THERAPISTS NEED TO REMEMBER SEVERAL THINGS:

1. You are not alone in the distress you are experiencing. Watching your patients suffer because of economic brutality is agonizing. That agony is shared by your colleagues in other areas of health care. Caregivers for the mentally ill must terminate services to patients who are depressed and anxious, who are botching their relationships, losing their jobs, and trying to cope with personal and societal disintegration.

2. You are not innocent victims. Not just rehabilitation professionals but most of us involved in health care participated in killing the goose that laid the golden eggs. We wanted state-of-the-art facilities and equipment, higher standards, increasing status and compensation. Most of us wanted to "build" and "grow" and thus contributed to and benefited from the runaway costs of health care. That fever of rising expectation, like many unchecked fevers, resulted in the terrifying convulsion of cost control in which we now find ourselves. However, we are not helpless, and we need not be passive. Taking the victim role is the worst thing we can do.

3. You can decline to become part of the problem. Don't let anyone call you a "provider." That is a strictly economic definition, and it is unworthy of you. You are health professionals. The distinction is that health professionals' behavior is anchored in a code of ethics. Principles such as beneficence, autonomy, justice, and truth telling are central to your work and your self-definition. Although caregivers need to be able to adapt constantly and swiftly in a world of tumultuous change, they must hold to a core of abiding values and principles.

4. See the context. We are in the midst of a high-impact collision between two antagonistic belief systems. The currently ascendant system views health care as a commodity subject to market forces. Care, compassion, and service are used for marketing but are regarded as sentimental when economic decisions are made. The other belief system, deeply embedded in American culture, acknowledges the powerful social, psychological, and spiritual significance of health and health care. Sick people seek the meaning of life, death, and suffering. In trying to gain access to health care, they are concerned with issues like equality, rights, and justice.

The pendulum is starting to swing back. The abuses and excesses of managed care in general and HMOs in particular are fast becoming known to the body politic. NBC and CBS have run exposés on the incomes of HMO executives and many stories about denials of necessary care to deserving patients. States are legislating protection for patients, such as laws requiring 48-hour hospital stays for uncomplicated deliveries. California has just instituted an 800 line for patients who have problems with an HMO. Suing HMOs has become a burgeoning new subspecialty for lawyers, and juries are awarding huge judgments to patients.

Stephen E. Lammers, Ph.D.

*Department of Religion
Lafayette College, Easton, Pa.*

THE REHAB COMMUNITY HAS always been an alternative community in modern American medicine. It has always been underfunded. Its struggles have never captured our imagination or our resources. Yet it has persisted in its belief that its work matters and is an important component of

The rehab community has always been an alternative community in modern American medicine.

It has always been underfunded. Its struggles have never captured our imagination or our resources.

any health care system that purports to offer a continuum of care.

The rehab community cannot sustain itself if it refuses to protest the limitations that managed care places on its work, if it engages in behavior that puts its patients at risk, if it "creatively documents" (that is, lies), or if it ignores what others do. The rehab community will have to go public with its concerns, recognizing that it will not be popular when it does so. Rehab professionals will have to "hang in there"—not because of promised success but because that is what rehabilitation is all about. They expect their patients to persist even when those patients have no expectation of success and are despairing. Now rehab caregivers will have to do what they ask of their patients: go forward in hope. It is up to the rest of us to sustain them in their journey.

Susan Dorr Goold, M.D., M.H.S.A., M.A.

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THE COMMENTS OF THE THERAPISTS quoted above (p. 4) illustrate more than any statistic that the resources available for health care are limited and that difficult choices between competing needs must be made. Although it is tempting to blame managed care for this situation, many traditional insurers have always imposed restrictions on rehabilitation services.

Managed-care organizations, however, as payers for and providers of health care, must take on some of the responsibilities, including competence, compassion, and fidelity to the sick, that individual providers have had. They must balance these against prudence, stewardship of resources, and fidelity to the not-yet-sick. This provider role, and not the need to constrain resources, is what distinguishes managed care from other insurers.

The problem here is that chronic, rehabilitative services have been less valued than "rescue" or acute-care services and thus are more easily (in the insurers' eyes) forfeited. This is particularly true because rehabilitative services serve, disproportionately, the chronically ill and disabled. Insurers are most concerned with pleasing (that is, are more accountable to) the healthy majority and employers. So insurers can make the small population of

Insurers are most concerned with pleasing the healthy majority and employers.

needy members very unhappy without having this injury register on satisfaction surveys or other aggregate measures of "quality."

What is a virtuous health care professional to do? First, continue to advocate for your patients, indeed for all patients, even those who haven't yet been injured. Recognize that some limitations are inevitable and even morally desirable if we want to avoid spending all of our resources on health care. This may require working with insurers to set reasonable guidelines for rehabilitative care. Exceptions, predictable given the variation among individual patients, would require justification. Once guidelines are in place, honesty would uphold and reinforce the system's fairness; "gaming the system" would become even more morally problematic.

Likewise, create a liaison with the for-profits' therapists. Chances are they feel as you do, that part of their mission is to care for the vulnerable. They may be able to bring pressure on their own organizations to uphold some community responsibility. A gentle reminder that they would end up with all the "charity cases" if you went out of business may help grease the wheels.

Last, work to improve the fairness of your organization and the extent to which it is held accountable to the sick as well as the healthy, to the members as well as the employers. Honest, public conversations about the choice between, for example, keeping very-low-birth-weight babies alive and providing the extensive rehabilitative services that such babies need to achieve their greatest function may foster the productive moral conversation that is needed in order to distribute limited resources fairly.

Summary and Conclusion

Daniel O. Dugan, Ph.D.

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THERE ARE SEVERAL POINTS OF CONSENSUS among the four commentaries above.

1. *It's cold out there.* The managed-care environment does threaten patient well-being and caregiver integrity in rehabilitation medicine.

2. *The threat is spiritual and political, garbed in economic clothing.* Who will stand and speak for persons disabled by birth, injury, illness, and high-tech medical salvage operations in a health care system perennially indifferent to the needs of rehab patients and currently self-identified with corporate and industrial practices?

3. *Rehab professionals can help rehabilitate our health care system.* Therapists should not "sell out" their patients or buy into viewing themselves as technicians or "providers," nor should they

fudge on their documentation. They should, individually and collectively, document their efforts and their outcomes to show the benefits to individual patients and their stewardship of shared resources. They should engage insurers in ongoing dialogues about the multiple "payoffs" of empowering patients to care for themselves and to work again. They should tell their stories, speaking out as a profession in public, in the press, and in political forums.

And yes, they should hang in there. Like the earth in our solar system, the world of rehabilitation medicine may seem small in the universe of health care. Yet its commitment to caring—with integrity, teamwork, and an acceptance of limits—makes it an ongoing experiment with health care on a human scale. And is not health care on a human scale just what we need now? □

BOOKS (continued from page 3)

narrative, the chaos narrative, any coherent structure in the individual's life is in shambles, and the expectation is that health (and life) will not improve. Frank actually considers these stories as non-narratives because those living through them have no distance from their experience and consequently no reflective grasp of it. Such narratives are ultimately beyond speech. The third, the most desirable type of narrative from Frank's perspective, is the quest narrative. Here the storyteller meets illness and suffering head-on and uses them as opportunities for change and growth, for the remaking of her self and her life. The body type in these stories is the communicative body, and quest stories are the *ethical practice* of communicative bodies. Such stories have an element of witness to them, namely, the witness of a change of character through suffering which is oriented in part to others for the benefit of others.

Herein lies what Frank calls a narrative ethics. "Because the pedagogy of suffering is taught in the testimony of illness stories, the kind of ethic it supports is a narrative ethic" (p. 154). The key questions posed by such an ethic are, What good should one want for self and others? How should one live a good life while being ill? Narrative ethics is an "ethics of commitment to shaping oneself as a human being. Specific stories are the media of this shaping and the shaping itself is the story of a life" (p. 158).

Like other works by Arthur Frank, this book is wise, insightful, and eloquent. It is born out of Frank's own experience of illness and creation of illness narratives, his attentive and perceptive listening to the stories of others (some of which he weaves through the book), and his own scholarly work, particularly in the area of sociology of the body. It should be noted that people who are familiar

with Frank's *At the Will of the Body* or his essays in *Second Opinion* will find *The Wounded Storyteller* decidedly more scholarly and academic in tone. The language of sociology of the body used here may be foreign to many. But serious readers should give patient effort to mining the riches of this text, for it has much to offer.

For those who are ill and those who care for the ill, this book provides a framework for better understanding the challenges that ill people face and the multiple ways in which they can respond to their illness. This in turn can lead to increased understanding of self and others, more attentive listening to people's illness narratives, and more appropriate ways of relating. It can help us get beyond the dominance of the medical narrative.

This book also implicitly addresses one of the pressing questions of our day—whether suffering can have any meaning. Without appealing (at least explicitly) to religious explanations, Frank makes the case for giving meaning to illness and suffering and even sees this effort as a moral activity and a moral duty. In fact, by holding out the communicative body as normative and proposing the quest narrative as most desirable, Frank challenges people who are ill to give meaning to their illness and suffering. There is much to be pondered here.

Finally, this book makes a most important contribution to what is called narrative ethics. Much of what goes by that name is about narrative, but not about ethics. It never deals with the normative considerations that are essential to ethics. The normative, however, lies at the core of Frank's discussion of narrative. His is truly an attempt at narrative ethics.

The Wounded Storyteller is a rich book that will appeal to a number of interests. It is a testimony to what can result from the experience of woundedness. □

In this issue: Does Managed Care Disable Rehabilitation Therapy?

REFLECTION *(continued from page 1)*

our food from a young woman with yellowed fingers and a hairnet. She smiles and gives me more rice when I ask.

Conversation with Dad is, of course, strained. I cut his food for him, which embarrasses me. I try hard not to watch his mouth; I am fearful he will choke on every bite. I help him spread tartar sauce on his fish, a guilty pleasure. We finish off with tea and arrowroot cookies. I long for easy talk, but what I really want is to make him laugh. It seems that's been my job for the past months, but this day I'm all out of jokes.

We start back to the floor after I've cleared the tray and helped Dad to wipe his mouth, my fingers shy at the intimacy of it. The sky is dark gray now, with the last reaches of sun scratching the bottom of the clouds. It's harvest time. The days have shortened around Dad. As we leave the nearly empty cafeteria, the cleaning lady swoops down on our mess, the last table to be cleaned. "Seems we closed the joint down, Dad," I say. He smiles.

The hallway outside the cafeteria entrance is wide and highly polished, lined with handrails as are all the hallways here. Gray tile and pale green walls. If you turn to the left, as most people do, you follow the hallway to the foyer and the bank of wide-mouthed elevators. If you turn right, you'll reach, in 20 steps or so, a door to the outside. It's a glass door with a panic bar cutting across its middle. Near the red-lit EXIT sign stand a seldom-used coffee machine and a chair.

Out of the corner of my eye this evening I see, silhouetted against the dying brightness of the fall sky, a dark figure in a wheelchair, looking out the door. Dad stops and motions me to go toward the seated figure. I'm a little annoyed at this; I'm tired, I've had enough. I do as he asks.

The ribbon between my heart and my father is red, the color of passion.

The figure turns when she hears us approaching. I can see her better now. I wince and slow my step. It's the woman who has been burned. With nose gone, eyes scarred wide open with no lashes, mouth twisted, she looks unhuman. Her hands resting on her lap are missing most fingers and look sore and raw. Her neck is a knot of red, blue, and purple tissue. She frightens me and shames me. I've seen her from a distance before, and she has always seemed to me somehow naked.

Dad moves close to her and smiles at her and starts to talk to her. His words are unintelligible but full of meaning. In a moment she is nodding and smiling at him. She does not speak; they say that shock has burned her words away. I stand by the coffee machine and watch. My Dad squeezes her hand as he squeezed mine and wishes her a good night. I take him back to his room and kiss him good night before heading out into the darkness.

The ribbon between my heart and my father is red, the color of autumn. □