Special Communication

Being There: On The Place Of The Family Physician

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There is a bend in the river that often reminds the doctor of his failure.

—John Berger

House staff dribble in, clack lunch trays down around the center table, and stir up their collective energy before the start of the Noon Case Conference. I take a back seat and fix my gaze on the blackboard. The particulars of today's case are condensed there in acronyms and milligrams per deciliter: they concern a 40-year-old Nicaraguan woman with a 7-year history of migraine headaches. A second-year resident now rises to begin, and I ease slowly back in my chair. His lulling remarks will soon drift into daydreams and afternoon agendas.

But the medical history unsettles me, battering the poor patient like a stoning. Not only from migraine does her head ache: she is fully disabled from prior stroke, has cervical disc disease and osteoarthritis; she has glaucoma and a history of nasal fractures thrice repaired; moreover, she is bothered by recurrent chest pain and admits to three psychiatric hospitalizations for attempted suicide. My stomach tightens, and I shift uncomfortably in my seat in sympathy for the resident. Will we accept his explanation for the headaches, even "for the purposes of discussion"? Can we ignore the emotional havoc of civil war and cultural upheaval and the part it plays in her pain? Does the resident suspect my own reluctance to care for these kinds of patients, whose problems are so insoluble?

We quickly digress to the usual debate: the choice of this drug over that one, side-effect profiles versus "the efficacy in my experience." Then a pause. The resident seems to capture, and now repeats for our benefit, something once disclosed to him by his patient. "Whenever I get a headache," she had confessed, "I first take the pills you gave me. If it continues, I do my relaxation exercises. But if it doesn't go away, after that I call you and we talk and it gradually eases off." So here is the physician's balm, in hands so eager, unscuffed, yet clearly capable: his patient asked only that he be there, to talk when she could no longer manage the pain alone.

Lessons like these are long in coming and easily overlooked in our rush to draw the pathophysiological correlation or initiate a drug of choice. But they are central to our work in primary care; they pierce to the heart of helping. In a posthumously published collection of vignettes, Lockhart McGuire taught us that "listening, talking, and writing can sometimes be as mighty in medicine as the stethoscope, the scalpel, and the scanner." [1] He paid attention to the whole life of the patient—its unpredictability, paradox, and individuality—because to do so was "good science" and spiced his labor with excitement and fulfillment. In listening to the patient's story, suggests Michael LaCombe, we live the case history along with the patient; the story unfolds and the physician is part of it.[2]

Continuity of Care

The first aphorism of Hippocrates (*ars longa, vita brevis*—art is long, life is short) warns the new physician that the greatest rewards in medicine come as a long shot. The notion of "continuity of care" reflects this ancient wisdom. The words themselves emphasize the importance of a connected and unbroken course, of inherent qualities that continue without essential change in the lives of our patients and over the course of our careers. In listening to the stories of illness over countless sittings or at the moment of truth, we become attuned to the whispered qualities of a person's life, the essence at risk in the throes of illness. And in so doing, with human presence

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and the comfort of words, we can help bridge a gulley where the road washed out.

Continuity of care has always enjoyed a privileged place in the rhetoric and repertoire of family practice. Yet the framers of our constitution—the original signers of the Willard Report—left its meaning ambiguous. Does it reflect an attitude that the family physician's "concern for the patient as a whole and his [*sic*] relationship with the patient must be a continuing one,"[3 p 12] or does it specify a duty to "insure the ready availability of medical services, 24 hours a day and 7 days a week, services that he either gives personally or arranges"?[3 p 8] And wherein lies its value? Is it because it resonates with our clinical experience and instructs our moral character or simply because it seems "good practice" and measures up to social expectations?

The debate in family practice literature, belying the specialty's need for renewed discussion, has been ridden roughshod down a one-way street. We read about the encroachment of specialization, managed medical markets, and social mobility on the previously unfenced frontiers of continuous care. We are rallied to the defense of continuous care and weigh various proposals that would environmentally protect it, dissect it into component parts, demonstrate its economic rationale (which must have been there all along), or promote it to a national audience. But what has been gained by identifying these five dimensions[4]—the chronological, geographical, interdisciplinary, interpersonal, and informational—or employing the units of usual provider continuity or continuity of care (the fraction of visits to the usual provider, or the dispersal of visits among providers, respectively)?[5] Why are we reassured by the experience in England, where continuity is said to occur in 80 percent of patient visits to a general practitioner,[5] or alarmed by the dismal record in our training programs, where it has been shown that, of patients assigned to third-year residents and making four visits to the health center within a year, nearly one-half saw three or more different providers?[6] Is it astonishing to hear that the patients who return to see their physicians in sequential years tend to be older and have a relative abundance of chronic problems, that the young and acutely diseased are not so keen about such an opportunity,[5] and that surveyed patients[7] and family physicians[8] generally support this trend?

Gayle Stephens, in an essay honoring the 20th anniversary of the American Board of Family Practice, laments that "the recommendation that seems most in danger of being lost nowadays is its emphasis on continuity of care, surely as important as first-contact care. . . . Many of our other ideals are impossible to attain when there is no durable physician-patient relationship."[9 p 290] Some doubt its lasting impact for our maturing specialty, citing a Norwegian survey that found most family physicians (81 percent) in agreement that continuity of care has less effect in reality than in theory[4] and pointing to a dearth of major studies that convincingly link ongoing care to improved outcomes.[10] Dietrich urges us to go beyond the measures of usual provider continuity with the caution that "the easier something is to count, often the further it is from what really matters."[10 p 296]

What really does matter? The answer can be found in the stories we insist upon retelling, set in the workaday arena of patient care, wrought from the conflicts negotiated there. The stories are not simply about professional privilege or duty. They speak of invitations to share in a patient's struggle, of transformations earned in the aftermath of a wounded self-image, and of continuing relationships that situate us within the community and reveal our cultural selves. The trophies we dust off memorialize the victories shared by both sides or ennoble a cause that has cost us deeply all around.

Howard Brody sees the practice of medicine as a storytelling enterprise, where telling tales serves a healing process. For if "we wish to relieve the patient's suffering, [if we] realize the power of words and stories to give effect to this, and yet have no illusions as to the ease or power with which [the physician] can accomplish his [*sic*] ends, then we must view our task as an interactive process with the patient over time."[11 p 191] To discover what a bloodied tissue or the diagnosis of diabetes means to a patient, we must be willing to "take a history" seriously. We must weigh the chosen words, respond to a sense of timing, bracket the account of illness within a life's narrative. As Jerome Bruner reminds us, "People do not deal with the world

event by event, or with texts sentence by sentence. They frame events and sentences in larger structures which in turn provide an interpretive context."[12 p 101] The ideal of continuity of care requires both an appreciation of this larger frame and a dedication to help patients relocate their sickened selves within it.

Somewhere along the way we have lost moral direction in our work. We talk more and more of meeting contractual demands and professional ideals and less of responding compassionately to a neighbor in need. We strain to deliver medical services 24 hours a day and 7 days a week, only to find that our place in medicine is really the market—an amalgam of mall and the convenience mart—where family physicians provide "one-stop shopping" and "continuous service." And we have all felt the despair of spreading ourselves too thin, so that nothing is left for family and friends and nothing more can be offered our patients than superficial promises or a technological fix.

A greater danger lies in the moral poverty of the market metaphor: when "the customer is always right," what is left to offer? When we "let the buyer beware" through the exercise of informed consent, what more is needed from a fiduciary relationship? When we ride the crest of our cultural expectation for "product guarantees" and "extended warranties" in matters of health, what responsibility do we assume for an unaffordable system, a malpractice crisis, and the social disenfranchisement of the lame and dying?

As important as marketing is for the business of medicine, it is too sandy a soil for our professional foundations. There is more at stake here than our fair share of the health care dollar or a well-demarcated space in which to practice. The room we are looking for must have a view. We must return to what has been our greatest asset—the relationships that flow from practice.

Continuity of care boils down to being there for our patients. Realistically, it means being there when we can; when we are not defeated by sheer exhaustion, the rush of our job, a mistaken focus, the blush of sentiment, or the cry of our own neglected needs. The invitation to help is like a bookmark in an unfolding story, calling us to a brief passage where our lives interweave with our patients' lives, where the moral seems to matter to us both. A bookmark so placed, in life narratives rather than in legal contracts or ethical tomes, is the fundamental way we come to sense and make sense of our call to service. The meaning often becomes clear in the retelling, in sharing our passages of invitation, transformation, and connection with those we trust.

Invitation

Recently, a middle-aged Chinese woman was admitted to the inpatient service of our teaching hospital and was rightly observed by the intern to be agonal. Her widely metastatic lung cancer had now reached the stage of irreversible respiratory failure; chest radiographs, blood gas determinations, and her increasing obtundity confirmed the obvious. The most rational and ultimately humane course of action, as agreed upon by the team of providers, would be to lend support to the patient and her family in the final hours but not offer cardiopulmonary resuscitation or intubation.

The family, however, would not hear of giving up. The English-speaking son most fervently expressed this conviction, carrying his protest from intern to resident to attending physician to primary care provider on that late August evening as his mother lay dying. All members of the medical team came in to be present with the family, to make clear the mother's condition and the futility of any intervention; each must have wrestled privately with the other option—intubate and wait for the inevitable. Over the son's pleading, literally on bended knee, the team stayed the chosen course until death mercifully came. And despite the son's overwhelming grief, and his lashing anger at a health care system impotent and indifferent before death, something powerful was gained: an appreciation that power lay not with the authority to stay the course (which too often is our onerous duty), but in the compassion to stay close at the bedside when nothing more could be done.

During the ensuing week, the story resurfaced in a dozen different contexts, rippling out among the residents. In its varied telling, we retraced the events, weighed every word, in an effort to explicate our sense of powerlessness before a young man's fury. We wondered aloud whether the ventilator might have been justified simply

to give the son more time to say goodbye or to prove that we cared enough to give every available means a try. Our rationale become muddled: how much time, and prove what to whom? An emerging focus was the need to explore each individual reaction to being there. What compelled us to be present? Wherein lay the reward? The hard part, the *really* hard part, was standing in the thick of the son's grief and anger. Had we honored him by our presence, despite all his anger, so that in the end he might find honor in his expression of grief; had we suffered with him so that he might not suffer alone? Would we now keep the story alive by demonstrating our desire to see him in the clinic, by sticking with him as he sorted out his new life?

For the patient (and family) failing with terminal cancer, the uncontrolled diabetic who angrily refuses everything but a return visit, or the paraplegic whose frustration and despair cannot be surmounted, what can our methods promise? How are we trained to respond? The invitation to be there for our patients is an almost instinctive human response, especially when there is nothing more to be done. Time and circumstance and the clash of cultures may mitigate against a full analysis of our patient's pain, but they do not obviate the need or spoil our opportunity to acknowledge it, to give it due recognition.

Transformation

Stan Moody (name changed for anonymity) was a founding patron in my new practice; today he remains one of my most regular visitors. An encounter cannot pass without indulging myself in mixed emotion, flowing from that distant Saturday morning when I admitted his wife Myra to the intensive care unit (ICU). She had atypical chest pain but seemed stable, and the physical examination and admission laboratory studies disclosed nothing ominous. In leaving her ICU cubicle, I smiled my reassurances that everything would be OK. The spring day was unexpectedly sunny and crisp. At home, I grabbed the shopping list from the refrigerator door, tossed my beeper casually on the living room sofa, and headed off for groceries and a breath of fresh air.

My return was greeted by a desperate telephone call from the ICU nurse, who for the previous 10 minutes had been trying to page me: my patient was clutching her chest, fighting for every breath; would I mind coming to reevaluate? I raced to the hospital. As the nurse and I pulled Myra up in bed, I frantically reviewed her history and physical findings in my mind's eye, searching for some explanation of the unfolding drama. It was now my turn to reassure Myra that she would be OK, but my promises were coupled with a signal for the nurse to call a code. The team performed their familiar routines systematically; a step back, I became aware of my patient's unheeded pleas for help, my promises to save her, the grave but unforeseen dangers before, her death by the numbers. It was over; I thanked those present for their help and attention and slowly made my way to the waiting room and to Myra's family gathered there. Straightaway, I unburdened myself of the dreaded news. Her husband reached out his hand and motioned me to be silent, as if these inexplicable events were foreseen. "Doc, ya done all ya could, and I want you to know we appreciate it."

For the next several days and weeks, images haunted me: the routine, uncritical motions through which I had conducted the initial examination, the beeper tossed carelessly on the sofa, the frantic commotion in the ICU as we fought to save Myra's life, the reserved expressions and nods of my colleagues, whose formal audience I earned in committee presentations and hallway discussions. Nagging questions remained: was I too incompetent to read the most basic signs of clinical distress, did my disregard for the beeper represent an adolescent rebellion against my responsibilities, was I useless in a crisis, did I betray the confidence of my patients?

One impression would not desert me—the firm handshake of Stan, his expression of heartfelt appreciation, his reminiscence on a long and fulfilling marriage, his simple faith in a happier rest for his wife. Howard Brody suggests that it is the "doctor's work" to transform a patient's account of his illness into a reassuring story, which is often accomplished through the caring approach of the providers, within the structure of familiar rituals. This Saturday morning, Stan Moody carried out the doctor's work for me. Surrounded by his loving family, he helped me access the very human dimensions of my voca-

tion—the enjoyment I derived from my patients and my labors, the known capacity for error, the many temptations to relax one's guard or be careless in conduct, the simple need for understanding and forgiveness, so that life can go on. Clinical mistakes and professional misconduct must be scrutinized; a phyician sometimes needs to be reprimanded. But all stories of transformation—of forgiveness and healing—require a human presence, for which the physician may be the only candidate, and a caring that we must be vigilant to provide.

Connection

"Being there" lastly means being here, in this place and no other. Most of us "from away" have sought the craggy shores of the New England coast with the hope of establishing our lives on more solid ground or escaping the tyranny of our wounded past. The community obliges our dreaming. It cloaks its own poverty, addiction, and prejudice in the surrounding stands of pine, behind blankets of fog that roll off the bay, and within the leathery expressions of the native population. Topography and tradition are in cahoots to preserve our pristine imagination. John Berger[13] reminds us:

> Landscapes can be deceptive. Sometimes a landscape seems to be less a setting for the life of its inhabitants than a curtain behind which struggles, achievements, and accidents take place. For those who, with the inhabitants, are behind the curtain, landmarks are no longer only geographic but also biographical and personal. p 13

In *A Fortunate Man*, written by John Berger with photographs by Jean Mohr, Berger thoughtfully observes the practice of a rural Welsh physician and recounts the story of a 27-year-old woman with asthma and insomnia who came early in her illness to Dr. Sassall's door. Radiographs and allergy testing were negative; the asthma worsened. The physician was convinced that severe emotional stress underlay her condition, though the patient and her mother insisted otherwise. Two years later, Sassall became privy to news of an affair between the patient and her plant manager; he had promised marriage, but then abandoned her. Armed with this knowledge, the physician again brought up his discussion of stress, but now inquired directly after the plant manager. The patient froze, then forever retreated. Now 10 years later, she has structural damage to her lungs and survives on steroids; she looks after her mother and seldom leaves the cottage. Dr. Sassall still suffers his blundered opportunity to reach his patient and help her recover a broken past. Writes Berger, "There is a bend in the river that often reminds the doctor of his failure." p 23

Like the crosses that mark a highway fatality, I have geographic landmarks that tell of limitations and mortality and patients who remind me of an error in judgment, a mishandled argument, an evasion of needs. The drive north on Swanville Avenue takes me regularly past a turn where, one evening, a driver was late in negotiating the curve, hydroplaned over a sloping field, and came to his fatal rest in 10 feet of water. Further along, I spot a cottage, otherwise hidden in the thicket of trees, where a young man violently received his due for playing in drug traffic. Still further, where the road hugs its way along Swan Lake, caught between water's edge and a rocky cliff, a motorcycle merged with the unforgiving granite and scattered machine and rider for another 100 feet along that twisting avenue. As county coroner, I preside over the physical evidence of a Lord who, irrevocably, taketh away.

I encounter my own failures along the supermarket aisles, where I painfully sense the averted glances of Mr. Hillman, whose tardive dyskinesia resulted from a now doubtful prescription; or Mrs. White, whose husband endured a vasectomy that I was unable to complete; or Mr. and Mrs. Robinson, who left my practice without explanation after years of mutual devotion. The fact of these events is unalterable; I am left to find in them my own fingerprints, live with their consequence, and make amends whenever possible.

We cannot remain preoccupied in our dreams and oblivious to the community for long. With the settling of fall foliage, through the narrowly cracked door of a home visit, over countless routine examinations handled with care, with an enduring patience and gradual participation, a new and mutual future emerges. We become neighbors, friends, the face of authority to some, the butt of others' frustrations. We have stumbled

upon each others' secrets, suffered each others' capacity to err, come to respect and love the fragile lives with whom we are curiously entwined. Because of this, I hesitate in my clinical encounters; I angle for an objective view—so that whatever fresh opportunity it holds will not be startled or ignored or bullied by my presumption. With familiarity comes that uncomfortable tension of sticking to rules that easily enough bend, charging fees that inflict a tangible hardship, plying a curative course when the only realistic advance will be measured in terms of hope and perseverance. Being in one place long enough has allowed me to practice with an intuitive awareness of the limits, to cherish and strive for clinical anonymity, and to wrestle with the demands of familiarity. Placing stock in the long haul, it seems a fair enough bargain, a small price to pay for our mutual survival.

The limits imposed by this rural community reflect, of course, the universal strappings on the human spirit. The jutting hills and glistening bay rein in my wanderlust to the setting and circumstance at hand; the cycle of street festivals, school years, church calendars, and the seasons themselves remind me of time's silent march; the boarding up of Penobscot Poultry Plant, Waldo Shoe Factory, and U Otta Bowl, giving way to galleries, gift boutiques, and waterfront development, persuades me that closures and new beginnings are part of a natural cycle. I have seen too many elderly patients' marriages dilapidate under ravages of stroke, dementia, or the march of time not to appreciate that every productive life shares this arc. When a patient dies, I wonder at the familiar ritual of townspeople, who will pause and spade up the shared memories of wedding dances, jobs knuckled down to, hardships jointly overcome. Their gentle labor soothes a wound, fills in a rift in the common ground, where our neighbor is laid to rest. In listening to these stories, and now finding a voice of my own, I have come to see that our existence is less substantial, more ephemeral, and propelled in the tide of community action and collective memory that alone can pay these last respects.

The barriers to "being there" for our patients are not bound in the red tape of reimbursement schemes and managed care contracts. Nor do they necessarily arise out of rotations in the call schedule, the compressed demands of our patient load, or the Brownian motion of modern society. They lie in our presence of mind, our inclination to linger and listen, our rigor to pursue some grasp of the patient's narrative and thereby catch a subtle signal for help. If, in LaCombe's words, we let ourselves "become part of the case history—part of the story in which we play many roles—stories about that moment of sharing when all defenses are down, when nothing else matters, when lines of priority are drawn,"[2 p 891] we will be blessed with some of our finest moments in medicine. Everyday excursions onto the narrative terrain also can be equally rich—the simple recognition of anguish and valor in a patient's struggle against multiple sclerosis or in the recording, as obstetrician and county coroner, of our community's mortal exchange, new life for death.

None of these rewards, not a single entree into a patient's confidence, requires the facility for greeting on a first-name basis, a cleverness with depth psychology, or the sacrifice of time away from our families or a moment in solitude. At heart, we must realize that being there for our patients is a risky proposition, one that tugs at the limits of our qualifications to help or the threshold of our perceptions of need. It takes determination and skill but, more importantly, time and presence to become a healer within a community.

Continuity of care, not unlike the practice of religion, is more than an attendance record. It is the weight of an anchor dropped at the sickbed of a young child, as we attend to her fears and console her mother, and so resist the swift currents of our dutiful day. It is the dogged determination to get the gist of a patient's story, to be unmistaken about its moral, in order to recognize and rejoin the severed ends of an old man's life. It is a splendidly colored canopy where the stories of physicians and patients interbranch, where changing roles and evolving relationships of community life provide shelter for the long haul. It is mostly about being there, a presence over time, about knowing our place and holding ground.

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