



Realized medicine

To do no harm: learning to care for the seriously ill

Alan C. Mermann
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How can medical students learn to become compassionate physicians, sensitive to the intensely private concerns of others who are very sick? How will they prevent their potential lapse into the negative professional traits they will see in their future teachers: avoidance of the seriously ill and an unfortunate and all-too-apparent inability to talk about personal issues?

Despite the disparaging view of the medical profession expressed in this passage from Alan Mermann's *To Do No Harm*, the author's message is one of hope and encouragement. Mermann practised medicine for 28 years before retiring to become chaplain at Yale University's School of Medicine. Recognizing the needs of medical students as they struggled to learn to care for patients, he developed a first-year "Seminar on the Seriously Ill Patient" in which participants meet regularly with a patient volunteer (the "teacher" or "patient teacher") and are then given an opportunity to reflect on the learning that results. At this early stage in the students' training, there is no expectation of expertise or authority; the focus is on insights bestowed by the patient teachers. As the students learn to understand their patient teachers and their illnesses, a growth in self-awareness, as well as in the traditional skills of listening and talking, becomes possible. Although Mermann discusses the experiences of some of the students, his book is not a course description or how-to presentation. Rather, it is a reflection on the ways in which people react to serious illness and the difficulties that physicians face in providing compassionate and knowledgeable care.

Many of Mermann's ideas are illustrated by patient stories. Some of the

stories are sad, others are comforting, but all allow the reader to learn along with the medical student how to better understand serious illness and its meaning for patients – and for doctors. The volume begins with a brief outline of research into the characteristics and coping strategies of medical students and physicians. This is followed by thoughtful chapters on various aspects of suffering, the variety of human responses to suffering, and the search for meaning in life. The strength of the book lies in Mermann's ability to promote the reader's self-reflection on such complex and important themes with clarity, brevity and without jargon.

For physicians to meet the needs of their patients they must recognize not just physical concerns (at which we do, for the most part, not too bad a job), but mental and spiritual suffering as well. As a profession, we have acknowledged that we need to do better at meeting the emotional and psychological needs of patients. It is the spiritual aspects that seem to cause the greatest discomfort. Because so many of us view the world from a secular point of view, or are fearful of infringing on the belief systems of others, spiritual suffering often goes unrecognized and unmanaged. Mermann's accessible discussion of human spirituality and its relationship with illness is clear, down to earth and thought provoking. The meaning that our lives have for us and the inner, secret places from which we commune with whatever we choose to support us through our lives are aspects of spirituality in all of us. An understanding of our death in the context of ongoing cre-

ativity and purpose makes it possible to contemplate the unthinkable. Only by grappling with one's own spiritual nature is it possible to be of some help to patients struggling in this way.

Although Mermann clearly wants patients to benefit from compassionate and understanding care, the benefits that physicians gain from providing such care are tremendous. His last chapter, "The Realized Life of the Physician," discusses the possibilities that physicians enjoy for a meaningful life. The burdens of the profession (dealing with constant uncertainty, being privy to human weaknesses of every sort, and witnessing the plight of others for which one can offer consolation but not relief) are unchangeable, but the benefits are tremendous. Our profession allows us to do work that is worthwhile, is respected above many others, provides fascinating challenges and offers a financially comfortable life. And yet many doctors are unhappy. Mermann suggests that the reason for this is the failure of medical training to teach us to be engaged in the personal concerns, attitudes and convictions of people in our care. Although he does not use the term "patient-centred care," this is what he is describing, and he is convinced that caregivers suffer when they cannot meet their patients' need for compassion and empathy. Coming to terms with the futility of making judgements on the values, lifestyles and beliefs of others is also key. Achieving a sense of satisfaction must be difficult if not impossible when one is aware of patient attitudes and unmet needs that seem, from the physician's perspective, unacceptable. Mermann's reflections should stimulate readers to consider their own values and the meaning that their professional work holds for them.

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Room for a view

Freud's request

When I first knew Simon Rhoner he was in his prime: vigorous, self-assured, successful. He came to my office on a number of occasions and I admired him for his scholarship, his affability and his well-expressed opinions. Our relationship was collegial, and we always came to an understanding about any clinical matter. The only time I disagreed with him outright was when he brought up a theoretical case for active euthanasia. He wasn't surprised when I rejected his arguments: "I understand your position," he simply said. When I asked why he had raised the subject he stood up, paused for a moment, and said, "I have thought a great deal about this. We must all die, but sometimes the process achieves no purpose and is very unpleasant."

At another visit he asked if I knew about Sigmund Freud's arrangement. I didn't. Simon then told me about the cancerous growth that had been removed from Freud's palate in 1922, when he was 66 years old. Aware of the probable outcome, Freud asked his doctor to help him "disappear from the world with decency."

"Was Freud's request for active, or for passive, euthanasia?" I asked.

Simon looked me in the eye and said, "Active."

A short time later I found a biography of Freud and discovered that there was more to the story. Freud survived the initial operation and continued his work for another 16 years, despite 33 additional operations, considerable pain, and the discomfort of a large, ill-fitting dental prosthesis. In 1939 Freud lay dying in England; the cancer had eaten through his cheek. Tormented by pain and no longer able to eat, he reminded his physician, Dr. Schur, of their arrangement. Schur promised to give him adequate sedation, and the next morning he administered a

third of a grain of morphine. Freud fell into a peaceful sleep and died just before midnight the next day — roughly 36 hours after receiving the morphine.

I had known the Rhoner family for a number of years. Simon's wife, Kate, was an accomplished musician and gardener; their two children were, like their father, pursuing academic careers. At one point Simon spent his sabbatical year in Australia, with Kate. I missed my contact with him, but he came to consult me soon after their return. He seemed well, but there was a troublesome finding on the physical exam: a hard nodule on the prostate gland. We agreed on some routine investigations and a referral to a urologist. Soon after, a pathology report brought unwelcome news: malignant changes that extended to the outer limits of the gland. Simon was composed and matter-of-fact when we discussed the diagnosis and its implications. We accepted the urologist's recommendations for treatment, and six months later Simon felt like his old self. He was excited about his family's various projects and the imminent publication of the book he had written when on sabbatical.

He left me a chapter, in which he had written about the medicalization of life. He argued that fixing up bodies and keeping them going as long as possible served the system's material values, not the patient's needs. He deplored

the fact that, to demonstrate its power over death, the medical profession didn't hesitate to overrule the patient's wishes.

The following summer my wife and I spent an afternoon with the Rhoners at their summer cottage, which was nestled into the side of a rocky peninsula overlooking a long stretch of beach. The water was alive with white caps and spume; above, seagulls flew stationary on the wind. The setting had a natural orderli-

ness. Behind the cottage, trapping the last warm rays of the day, was a bedrock patio. The textured rock was bordered with lichens — pink, avocado and red. Beyond were dusky blueberries with a touch of autumn in their leaves, robust huckleberries and waxy bayberries, all ringed by salt-pruned spruce, the blue sky and the scudding white clouds.

From inside the cottage we could hear strains of classical music, and in the midst of the conversation, Prokofiev's *Dance of the Knights* surged out. Simon got slowly out of his chair, wincing as he went to close the French doors. He saw me watching him and explained, "I was wrestling with my son on the beach yesterday; I must have strained my back."

The next day he came to my office. The pain was worse. A bone scan confirmed what we already knew: the cancer had spread.

"I'm not interested in castration," Simon said bluntly.

I mentioned other options but suggested that the urologist would be the best one to advise.

Simon's eyes blazed. "Therapy to the end! A useless battle with death. Where is the healing function of medicine? Doctor, do we have an arrangement?"

I put my hand on his shoulder and said, "I'll be your Dr. Schur."

Simon saw the urologist and opted for a second opinion in a distant city. He started a new therapy there, and all winter long dutifully flew back and forth. He seemed to be holding his own, but in the spring the pain returned. By May he could no longer make the flights. I met with the family. Simon did not want any more treatment. He was experiencing a lot of pain and wanted to die at home. I started a program for pain control.

Two weeks later, toward the end of the afternoon, Simon phoned. "I'm in agony," he said. "It's time for an injection."

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Art Explosion



Lifeworks

Reading the times

The Art Gallery of Hamilton continues its *Countdown to the New Millennium* series with Cees van Gernerden's photographic and textual exploration, *Surviving the (dirty) nineties*, on view until Dec. 5. Over the course of two and a half years, the artist photographed friends and acquaintances — mainly artists, environmentalists, and community activists — and asked them to comment on their “hopes, fears, aspirations and expectations” in the 1990s. More pointedly, he asked them how one could survive the “assault on health, education and social programs” that has characterized this decade. Most of the photographs were taken in the participants' homes; van Gernerden used a small rangefinder camera that, as he explains, “looks like a kid's camera” and makes less noise than the more popular SLRs. The result is a series of 52 portraits in which the “subjects” are engaged with the camera in a frank, relaxed and dignified mode. The second textual component of the work, dispersed through the exhibit on four clipboards, is assembled from material culled from mainstream print media over the period of the project. Despite the mainly right-wing orientation of the sources, these excerpts reveal a concern with social issues. As van Gernerden remarks, “All of us are uneasily aware that our social fabric is coming apart by the seams.”

When van Gernerden immigrated to Canada from the Netherlands in the mid-1960s, he was looking for a more pristine and less populated place to live. He remembers the Trudeau years as “fantastic times ... the country was alive then.” But we have missed opportunities to set an example in our social programs and environmental stewardship. As in the Dirty Thirties, we are seeing a resurgence of homelessness, poverty and the degradation of natural resources.

Van Gernerden began the project in 1997, spurred on by government policies that amounted, in his view, to “the criminalization of poverty.” Rather than facing up to the problems created by cut-



From Cees van Gernerden, *Surviving the (dirty) nineties*, 1997–1999. Silver print. Collection of the artist. Stephen and Douglass Dozdow-St. Christian: “We’re Queer, and we’re a couple, so feeling marginalized, being marginalized, is a way of life, but we have a special sting here in Ontario during the last three years, because something mean and corrosive has turned the marginalized from people too long neglected into targets of wilful political attack. Something venal and divisive ... has polluted the social atmosphere. And then there’s Bill. He is a squeegee-kid who lives in an abandoned warehouse, and works under crumbling concrete of the Gardiner Expressway, washing the windshields of the increasing numbers of BMWs making their way to Queen’s Park We’re out there, somewhere on the margins, just like Bill. And just like Bill, we get by ... although more and more, we are getting by in a nasty and brutish province that has abandoned the poor, or worse used them as scapegoats in order to win votes; that has turned its back on the victimized.”



From Cees van Gernerden, *Surviving the (dirty) nineties, 1997–1999*. Silver print (detail). Collection of the artist. Judy Burgess, Paul and Zachary Ropel-Morski: "The 'Dirty' Nineties, for our family, has been a decade of 'ifs.' We'll manage if ... — our jobs and non-profit art galleries continue — if these galleries ... continue to receive government support — if we can afford the large increase to our house taxes — if no serious medical or dental problems arise ... "

backs to social programs, governments are "going after easy targets — squeegee-kids and beer-drinking mothers — as a political expedient." In *Surviving the (dirty) nineties* he wants to give a voice to the people "from a grassroots level rather than from positions of power." None of the participants have joined the ranks of the homeless, and many enjoy a comfortable lifestyle, but the apprehension expressed about what van Gernerden describes as "the hard-right turn in government" is a thought-provoking testimony of the times.

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Freud's request

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Simon looked gaunt and exasperated lying on his bed. I drew up the equivalent of the next increment of his oral morphine and injected it.

"Will it be enough?" he asked.

I took his hand and said, "I'll be here for you."

Simon closed his eyes, shook his head, and said, "I'm not going to say goodbye." Then he waved me out of the room.

Downstairs, his wife and children waited. They very much wanted to care for Simon at home and were keen on learning about skin care, lifts and transfers, and pain control. We made arrangements for nursing support, and I wrote out prescriptions for pain relief.

On my next visit Simon let me know he had been annoyed with me.

"Why?" I asked.

"You know why. I didn't say goodbye to you but after the morphine injection I half hoped not to wake up. Furthermore, you made arrangements with my family that were not discussed with me." He looked at me severely and then grabbed my hand. "I forgive you," he said. "Now I suppose you want to confirm that my heart's still pumping."

Over the next month Simon was remarkably free of pain. A daily routine emerged, one that clearly reflected Kate's

aesthetic sense. Every morning after breakfast she would help him downstairs to a comfortable chair that looked toward an eastern exposure. Here he had his coffee and read the morning paper. Simon showed me the view plane. Leading to the window was a vase of freshly cut flowers, and through the window was a small forsythia bush that would soon break into bloom. Next to the forsythia was a young serviceberry tree that in turn brought forth delicate white-brown blossoms. Beneath and around the splashes of colour were lush evergreens — junipers, pines and yews — and beyond the aromatic bark mulch and winter grass grew a slanting row of linden trees.

Late in the morning Simon moved to an alcove facing south near the kitchen and listened to music: Buxtehude, Bach and Chopin. The bay window was alive with colour: hanging plants merging with ferns and palmettos, through the window a thick spruce hedge, and above, in the distance, the sweep of a cedar-shake roof.

During the afternoon, in the family room, Simon organized his papers and worked on his correspondence. In front of him was a picture window overlooking the garden. Birds swooped into the feeders close to the window and then darted away to the shrubbery. This garden, full of wonderful highlights that merged and produced a whole, was in

the centre of the city, but it could have been in Bouchard, Belingrath or Kew.

After supper, Simon's daughter read him Chekhov, but as the days lengthened, his strength began to fade. One week he was actively discussing the points in the story; by the next he was falling asleep in mid-sentence. His daughter would finish the story, and then his son carried him upstairs to bed.

By the last week of June, Simon slept most of the time. The stories and music continued, and when I visited there was always a gentle smile on his face.

The evening of the first of July my wife and I walked down to the harbour to watch the fireworks. It was warm, with just a puff of wind languorously propelling the sailboats across the yellow and magenta water. The crowd stirred as the curtain of night fell and the first rocket sizzled high in the sky, exploding in reds and whites and blues. Beautiful variations of colour continued to build in the night sky into a profusion of sound and colour. Then came a pause ... and a single rocket arched high over the harbour, exploding in a magnificent, luminous blossom of bronze and silver and gold. In the awed hush that followed my pager summoned me.

Soli Deo Gloria.

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