



AIDS on the front line

AIDS doctors: voices from the epidemic

Ronald Bayer and Gerald M. Oppenheimer
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Last summer I was speaking with a novelist who lives down my street about my personal and professional experiences as an AIDS doctor. He strongly recommended that I publish, with other AIDS physicians, a record of our experiences or else risk losing a part of medical history. A few days later *CMAJ* sent me a review copy of *AIDS Doctors: Voices from the Epidemic*. The idea for this wonderful book had arisen in the early 1990s, during a dinner conversation in which the editors were made privy to the private reminiscences of three AIDS physicians. My novelist neighbour's suggestion came nearly 10 years too late.

AIDS Doctors is an oral history based on the recollections of 76 front-line AIDS physicians in the United States, including those who first detected and reported on the epidemic in June 1981. Canadian "AIDS people" (a designation assigned to the first wave of AIDS physicians in the US) will recognize themselves in this book, no matter what their background or experience.

The editors remark on the atypical demography of the physicians interviewed: 40% gay and lesbian, just under 50% Jewish, 30% women and 90% white. A leftist political philosophy, deeply held religious beliefs, a sense of moral duty and the excitement of a new disease motivated and sustained AIDS physicians through the first terrible 15 years of the epidemic. But it was gay physicians who rallied to the sides of their dying friends and lovers in numbers "out of all proportion" to their representation in the medical profession. Many openly declared their homosexuality, almost in defiance of the deadly epidemic sweeping their community.

AIDS Doctors provides a blow-by-blow account of the bewilderment and shock felt by physicians who first encountered an unknown killer of young gay men. Physicians, some reluctantly, were quickly connected to communities of HIV-infected people with whom they shared no common experience or values: injection drug users, the poor and (for heterosexual physicians) the gay community. It was a struggle — described in brutally frank interviews — to overcome the barriers between mostly middle-class physicians and dying, destitute patients. And it was their helplessness in witnessing the march of their patients to death that impelled most AIDS physicians to return to the most noble traditions of medicine: kindness, compassion and availability. Death and dying also forced these physicians to cede power in relationships that they traditionally dominated. HIV-infected people demanded participation in all decision-making, whether at the level of patient care or of public policy, leading to a so-called "more democratic" medicine.

The epidemic profoundly affected the lives of AIDS physicians who, as one of them put it, became "gripped." Fear of infection, occasionally to a near-paranoid degree, tested a centuries-old ethical conflict between the values of self-interest and of self-effacement. Requests for assisted suicide, the demands for unapproved and

unconventional therapies and the need to enrol poverty-stricken patients in clinical trials as a means of securing medical care regularly confronted American AIDS physicians. The dumping of AIDS patients by physicians who refused to treat them, institutional antagonism toward AIDS doctors and professional isolation produced clusters and networks of AIDS physicians who relied on each other for mutual support.

The traditional separation between doctors and patients collapsed, particularly in the gay community, in the throes of death. For heterosexual physicians the bonds of family life were severely strained as they poured their energies into all aspects of the epidemic. One highly visible doctor recounted a conversation in which his young child stated, "I don't want to see a TV Daddy; I want to see the real Daddy."

The intimate revelations published in *AIDS Doctors* will resonate with many AIDS physicians: the "illicit sense of exhilaration" at engaging with a new disease with its myriad manifestations, "tak[ing] chances and work[ing] on limited data," the "state of chronic depletion, sadness and fatigue" and the disappointment and exasperation of the zidovudine (AZT) monotherapy saga.

The assimilation of AIDS into mainstream medicine (the "normalization" of AIDS) has been wrought in part by the spectacular success of new treatments and the rise of early AIDS doctors into positions of professional prominence. But the

goodwill and commitment of the earlier years is no longer sufficient. The complexity of highly active antiretroviral therapy (HAART) requires expertise held by relatively few. The "ties and identities that so defined the lives of AIDS doctors" have broken down, and



Fred Sebastian

the solidarity has dissipated. One AIDS pioneer stated, "I would really prefer being on the frontlines again, doing something that's unique."

The subjective experience of Canadian AIDS physicians is accurately reflected in *AIDS Doctors*, with some noteworthy exceptions. Canadian physicians were not participants in the detection and initial description of the AIDS epidemic in North America. Canada's health care system guaran-

teed, in contrast to the US system, access to HIV care for patients regardless of socioeconomic status. The existence of a well-developed system of primary care meant that Canadian family physicians, particularly gay physicians, found themselves on the front lines of the AIDS epidemic in Canada.

AIDS Doctors provides for both medical and lay readers an intimate glimpse into the dramatic struggles of the relatively few physicians who first con-

fronted an epidemic of catastrophic proportions. It stands as a testament to the lives of physicians "gripped" by the AIDS epidemic.

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Room for a view

A Good Friday?

On a Wednesday afternoon I got a call to the ER. A middle-aged man had been transferred, unconscious, from another hospital after a suspected intracranial bleed. A tearful daughter was with him, and I spent some time with her as we waited for the results of the CT scan. He was transferred to the ICU, and for the rest of that day anxious relatives came and went.

On Thursday it became clear that the patient was not going to recover. The team began the careful steps to determine whether he could formally be declared brain dead and began the precise therapeutic dance to keep him that way. Later in the afternoon I went with the attending physician to let the family know that their father was being kept in that nonlife we call brain death. Then came the tentative suggestion about organ donation. The family was surprised. The patient had been both a heavy drinker and a smoker: Who would want his organs? But they agreed. It seemed a strange irony to me that a few months before, in the same unit, a family had refused to allow the donation of organs from a young, previously healthy trauma victim. Perhaps we can beg, but we can't always choose.

The nurse from the provincial organ donation agency arrived, and I accompanied her back to the stuffy little family room to listen as she went through the long list of screening questions with

the family. Has your father had many sexual partners? Any homosexual partners? What medications was he taking? The litany seemed remorseless, no matter how gently canted. (Did we really learn any infallible truth from these questions? Or did we protect our own interests at the family's expense?) By now it was evening, and the family were exhausted.

So they said goodbye to a dead father who looked alive, with his chest rising and falling rhythmically, his urine draining and the monitor traces threading evenly across the screen. Some families say goodbye through the ritual of a bedside prayer, but not this one. They left without ceremony, with just the sympathy and support of the staff. And when they were gone I asked to watch the organ retrieval.

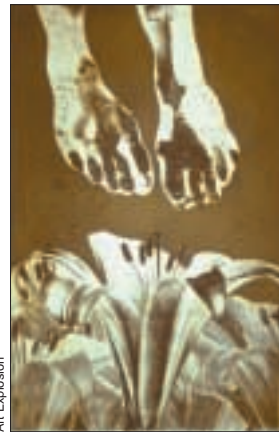
I was fired up to make this request by an education session on organ donation that a fellow chaplaincy resident had recently organized. I don't know if I was more worried that the staff would say no, or that they would say yes. The organ donation nurse had no objection,

and as it would take several hours to put retrieval teams together I went home for a while. The nurse paged me at midnight, and I drove too fast back across the city, worried that they would start without me. I wondered what I would say if I were caught speeding, and what the police would make of my bizarre excuse.

When I arrived the ICU was quiet, the patient was stable, and I wondered what to do next. A perfusion technician came into the unit, and taking a deep breath I explained that I would like to watch the retrieval. As if this were the most normal request in the world, he took me back to the operating suite where, feeling rather stupid, I repeated the request to two women in surgical greens. They suggested

I get changed. I picked out some clothes that looked about the right size and put them on in the deserted changeroom. I was instructed to put on hair and shoe covers, was shown to a spot at the edge of the operating room, and was told not to touch anything.

I felt a stranger in a different world. Here, the role of chaplain was superfluous, meaningless. I wondered how to stop my glasses misting up behind the mask, and surreptitiously experimented



Art Explosion

with moving the mask up and down until the fog cleared. I was sure that the physical aspects of the next few hours wouldn't upset me — would they? The radio in the corner was tuned to a lite-pop station, and I pondered the distance between the saccharine music and the reason we were there. I found myself praying — for the staff, for the patient, for the recipients, for me. Eventually, the patient (or was he a body?) arrived. I could not hold “alive” and “dead” together in my mind, even though I was seeing it. I was struck by the gentle way he was transferred to the table, and how much care was taken to cover him. Perhaps it was easier to pretend that he was alive rather than dead.

The teams from London and Toronto took longer than expected to arrive; it was pouring with rain, and there were cell phone conversations detailing just how close they were to the hospital. Just like my “put the oven on” calls as I leave work. Very ordinary, somehow.

And then it was all business. He was shaved, swabbed, covered with surgical drapes. One of the surgeons suggested I move closer for a better view. I did, and wondered if watching the first incision was a good idea. What was so natural for these people was not so for me, and I was glad of the mask to hide behind. I worried unnecessarily, because it was impossible to be anything but awed by the careful and precise way that the surgery proceeded.

As I stood and watched, I wondered about the recipients and their families. It was a dark and rainy Easter weekend where they were, too, as they made the necessary last-minute arrangements. They must have gone over this in their minds many times before tonight. What anxious dramas were being played out as friends and relatives called each other with the news that tonight was the night ... I became aware that Holy Thursday had become Good Friday. This one patient, through his expressed choice and his family's consent, was going to give new life to possibly five people, and new sight to two peo-

ple who were becoming blind. For me, the Gospel parallels were profound. I was already a witness to a death that allowed a sacrificial gift to redeem the lives of others and offer the hope of resurrection.

The teams worked on together, and at last the patient's own blood supply was replaced by the perfusion solution. Then, first the liver and then the lungs were lifted like a baby from a sectioned womb and placed almost reverentially in basins surrounded with ice. The teams checked their prizes again, packed up their gear and left. After the long drive back to the recipient's city, the same surgeon would transplant the lungs. He didn't take the heart; in the end, it wasn't suitable. Someone was going to be disappointed: no resurrection for them just yet.

Another surgeon came to retrieve the kidneys. No big rush here, nor for the corneas. They would be recovered at a civilized hour later in the morning. Finally, everyone was gone except the two nurses and the chaplain. The place was a mess. The body was a body, plundered and, yes, now dead. I felt as though I should pray, give some sort of benediction. Never at a loss for words, suddenly I could find none, and my dismissal was silent. One of the nurses commented that everything went more smoothly than usual. I joked that it was because there was a chaplain present. Perhaps I was only half joking. Maybe having anyone observing would have had the same Hawthornian effect, but I know that I really did not need to go to the Good Friday service later that morning. We had enacted it in the operating room, and it had been a sacred time and space.

Later, when I told my supervisor what I'd done, he mused that I should perhaps go and check the morgue on Sunday morning.

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The other patients

Critical care units
and intensivists.
Probes and inotropes
intubation, ventilation
stents and tiny balloons.
A little wedge pressure
a little wedge driven
between doctor and patient.

Separation, isolation
“isolette” is no better
when a child faces it.
Barrier nursing:
a cruel oxymoron.
They need
the most and the gentlest
touch
These isolated ones
in the sterile rooms.

Mothers stand by, speechless
Fathers pray, silently.
Partners wait for life.
These are our other patients.
Magic bullets
intravenous cocktails
to render senseless
have not paralysed them.

Time to get back to the bedside.
To touch the patient
to touch the family.
The latex hands
and masked faces
the curious cloaks
and stethoscope necklaces
must become more tender.

The others need support, too
for visitation
not isolation
in the ICU.

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Lifeworks

Tangles

As an introduction of my work relating to Alzheimer's disease and other forms of dementia, I recently exhibited a suite of six original copper-plate etchings at the Moose Jaw Art Museum. This first set of prints from this ongoing project specifically relates to my maternal grandmother's affliction with old-age dementia.

Each print is a culmination of disconnected images, which imply a fragmentation of thought but are also a construction of narrative. They may be a resurrection of my grandmother's memories, faded or romantically clear, but generally they make reference to various events in her past and present environments. *Big Ben* alludes to her homeland, England, which she often used to speak of. One of my grandmother's favourite foods is french fries. In the past her favourite was fish and chips, but now it's just the chips — perhaps only because of the ease with which she can eat them by herself without making a mess. Symbolically or physically, many layers of memory, whether hers or a family member's, are included in each image.

The orange rice paper behind the assembled images contains the same



Diane Lara, *Big Ben*, 2000. Etching with caned Arches paper, 57 cm × 100 cm

black markings in each piece. These markings were made by rubbing the metal plates the prints are made from against the bricks and concrete of the permanent-care home where my grandmother lives. This represents the environment she is now familiar with: it has firm boundaries and is small and contained, but safe and secure.

The actual caning (weaving) of the paper, which is consistent throughout my work, symbolizes an attempt at control. As I weave each strand of paper I think of how little or how much control relates to a specific image or thought. Perhaps there is very little control, which is often represented by a single, sometimes broken, strand. The actual physical weaving of the paper symbolizes a reorganization or “untangling” of the abnormal fibres in the cerebral nerve cells of dementia patients.

A horizontal band of weaving placed at the same point across each picture plane (and worked into, around and through each smaller image) represents the brain's neural pathways. The loose strands of paper at either side represent abnormal fibres, which create a disruption of communication; hence, the messages lose their way at the synapse (the physical space between each work mounted on the wall). The detail of *Empty Presence* shows the weaving process involved. A finely netted gold thread placed over the horizontal strip of caning represents that last, fragile hold on sanity.

While walking through the gallery contemplating each image, the viewer hears a voice in the background — a voice with a slight British accent, quietly speaking of nonsensical, unrelated things. It may be interrupted by sobbing, or possibly by intercom beeps reminiscent of hospital sounds. The voice comes from a video at one end of the room, while photos of the woman in the prints and of various family gatherings fade in and out across the TV screen. This is dementia.

Diane Lara
Moose Jaw, Sask.



Diane Lara, *Empty Presence*, 2000 (detail). Etching with caned Arches paper, 57 cm × 100 cm