

LITERATURE, THE ARTS, AND MEDICINE

Discussion

David L. Clark, Ph.D.

The first of our columnists, S.M. Barber, is a Canadian born academic living and working in the United States who has taught seminars on the subject of living with HIV at McMaster for many years. Sharing his own long-time experience with HIV while also discussing the larger social issues associated with the history of the epidemic in a North American context, Barber regularly faces classes filled with undergraduate students who, by their own admission, have never before knowingly met someone with HIV (and who, perhaps more strikingly, often assume that no one in their classes is HIV+). Barber's unusual frankness and rigour ensures that these classroom encounters are illuminating and in some case unsettling for students, whose knowledge about HIV can now be tested on the pulses of a person for whom the subject is more than curricular. Barber tells us that he has himself been transformed by these seminars because they have given him an opportunity to consider his ongoing and always changing relationship with his HIV. His contribution to MUMJ is but one more step in that onerous labour of self-examination—a palpation of the mind and body, if you will, to which Barber has committed himself since testing positive some years ago. It is worth emphasizing that Barber chose to make this column, along with his classes at McMaster, the first occasion in which he has discussed his history with the virus outside of his health-care providers and his American-based support group. Needless to say, speaking publically about HIV is not without a host of complications, reminding us that HIV/AIDS remains a uniquely fraught social phenomenon as much as it is a medical one.

Yet Barber is careful to insist that his decision to speak in these highly selective venues was not negatively the expression of fear, much less shame, but instead strategic in nature. Not speaking to a wider public has, over the long course of living with HIV, paradoxically become a way to say something even more important; namely, that self-identifying as HIV+, like all acts of identification (“queer,” “woman,” “MSM,” to name three others), assumes that “identity” is the single most important way of understanding oneself and another. But is that in fact the case or always the case? The

processes by which a human being is identified and “known” remain an important part of making social existence meaningful, but an enormous amount of humanities scholarship has demonstrated since the early 1980s that these acts are imbued with power, and thus can be normative as much as they are descriptive. “Identity” is a topic that must be handled with great care: the advent of HIV/AIDS has made that lesson pressing as never before.

For this reason, Barber suggests, knowledge of his HIV+ status hardly begins to describe who he is or has been or will be in the future. HIV isn't for him a kind of passport of the self, to be given up at the request of the authorities. Declaring oneself to be HIV+ isn't as explanatory and self-consolidating as it is sometimes assumed to be; it doesn't make something essential about Barber transparently available to his listeners, much less to himself. It is instead a provocation to thought and ethical action, best understood as part of a much larger process of self-understanding that deliberately avoids the pitfalls of too hastily identifying and self-identifying. This complicatedly resistant and querying relationship with HIV, this insistence on making HIV the occasion for a radically new understanding of the self, has important philosophical precedents. As Barber writes, it was his great fortune to have grown up with the work of Michel Foucault, the widely influential social theorist who died of AIDS related complications in 1984, and whose late work is the intellectual force behind the emergence of the queer activism in which Barber has been involved for almost twenty years. As it happens, Foucault's work became a principle subject of Barber's research, but that is not the only way in which the French thinker plays a role in his life. From him, Barber also learned the importance of what Foucault calls “care of the self,” the classically inspired phrase he uses to describe a way of being in the world that emphasizes the contingent and self-devised nature of human existence. One must make oneself a kind of “practice,” Foucault argues, rather than let others tell you who you are once and for all. If being HIV+ means anything, Barber insists, it means working at negotiating and renegotiating its personal and social meanings, and thus living with the virus as if it were

a troublesome, demanding, and finally unknowable fellow traveler. About living with HIV, nothing is certain; as Barber suggests, learning to tarry with that incertitude is the difficult lesson that makes students of us all.

A great part of Barber's allergy to the very notion of identity is no doubt activated by the somber fact that it has often been put into the service of the worst stigmatization of HIV/AIDS. That HIV/AIDS has disproportionately affected gay communities in North America has often been used as an alibi to connect it fatefully to queer life, i.e. to claim, against all evidence, that it is primarily a "gay" disease. I recall that only a few years ago, some first year students I taught remained openly incredulous when they were told that heterosexual intercourse was the chief mode of the transmission of HIV in the world. Sometimes it seems as if more than two decades of AIDS education has yet to teach a basic lesson: the transmission of the virus has everything to do with practices, not identities, and thus with what you do rather than who you are. Teaching HIV remains a challenge, but our columnists put to us that the most eventful lessons continue to be the ones that the virus itself offers. The story told in Dale Guenter's column vividly makes the point. Guenter currently practices HIV primary care at the McMaster Family Practice, but his relationship with the virus goes back to the time before he became a physician. Indeed, the emergence of HIV in North America—a period of considerable confusion and half-knowledge about the virus—coincided exactly with his days as an undergraduate student, when he struggled to discern the contours of his own sexuality. This was an inauspicious coincidence, to say the least, for it seemed at the time to personalize the epidemic in the worst possible way, i.e., by connecting sexual pleasure with disease, and non-normative desire with death.

Although Guenter does not say so, this was an association that was undoubtedly fueled by a longstanding social prejudice that has, since the nineteenth century, unjustly associated homosexuality with illness and self-destructiveness, a prejudice that found an unexpected and virulent new life in the age of AIDS. With admirable frankness, Guenter suggests that his initial and intensely over-determined encounter with HIV/AIDS, at once vexing and difficult for him personally, cast a shadow on his early development as a medical professional. While in training he found himself keeping an almost unconscious distance from people with HIV, not because he was concerned about becoming infected, or because they represented patients whose enormous need for help felt understandably overwhelming for a new physician at a time when the treatment for HIV wasn't nearly at the place that it is now. As Guenter explains, his reluctance to involve himself more fully with the lives and deaths of persons with HIV symptomatically expressed an altogether different discomfort in him; almost without knowing it, he was unsettled by the chance that associating with AIDS patients

might implicate him personally, and say something about himself that he wasn't altogether sure he wanted said or known by others. It was indeed not infection that Guenter feared, but an altogether different sort of contamination; in spite of himself, the young physician felt out of control of the meanings that others would attach to him merely because of his working proximity to HIV and HIV disease. In the early days of HIV/AIDS, Guenter's experience underscores, the social and cultural context of the epidemic that played a significant role in how it was understood, experienced, and treated, and not only by HIV+ individuals. It still does. A disinterested demeanor undoubtedly plays a key role in the practice of medicine, but Guenter's remarks remind us that physicians are finally like everyone else, fully embedded in the culture in which they practice, and thus shaped, for better and for worse, by the societal expectations and assumptions that are always at work there but especially at the nexus of identity and sexuality.

I say "shaped" by these forces, but of course there is nothing preventing a mindful physician (or, for that matter, an equipment mechanic or English professor, the professions of our two other columnists) from responding in turn to the environment in which he or she lives and works, or from radically retooling his or her assumptions about illness and identity. Guenter's experience forcefully proves the point. Although he may once have turned away from HIV, HIV had a strange way of catching up with him. Practicing in an inner city clinic serving an HIV+ population, Guenter began to meet and reflect upon his fears, compelled by the implacable needs of his patients to revise his assumptions about the ways in which his life and work were unavoidably intertwined in the age of AIDS. After Barber, and in memory of Michel Foucault, we would call this transformation a "practice of the self". What did Guenter learn from HIV – or rather, what sorts of things is it teaching him still? The short answer would be nothing short of everything, so far-reaching is the still unfolding lesson at hand. For as Guenter suggests, working with his patients has subtly and utterly altered his sense of himself as a physician, at once clarifying and complicating his role as a health-care provider for those for whom HIV/AIDS is so very much more than an infection and a syndrome.

To be sure, HIV/AIDS is a biomedical phenomenon, but it is also a deeply affecting and globally important crisis of meaning (or "an epidemic of signification", to recall a useful phrase from Paula Treichler), a uniquely wrenching moment in human history that challenges the very basis of our understanding of what it means to live and to die, to be ill and to care for others, a moment, moreover, that brings out as never before – for those with the eyes to see it – how social and cultural inequalities largely account for the shape and scope of the epidemic world-wide. These inequalities and differences call out for critical understanding and above

all action, both near and far. Like the environmental catastrophes also haunting our times, HIV/AIDS makes a clear cut distinction between the two universes – the local and the global – ultimately untenable. “African” HIV/AIDS is different from HIV/AIDS in North America, but we must always be wary that in emphasizing that difference we don’t forget that it remains our unwavering obligation to do something about it both here and elsewhere – not tomorrow but today, and as a promise made in earnest of tomorrow. HIV is his “most important teacher”, Guenter tells us, one of whose greatest lessons has been that healing others means not curing a patient but bearing witness to his or her irreducible singularity, as exhausting, unpredictable, and unteachable as that work necessarily is. As Dr. Guenter suggests, we must seek to do justice to the epidemic as well as know what it is.

Peter Horner, our final contributor, concludes his column by telling us that he has AIDS, and that piece of information means that he is on a path that is different in important ways from the one that Barber walks. The distinction between being HIV+ and having AIDS is of course incomparably relevant for a host of reasons – personal, social, and medical. Too little attention is sometimes paid to the difference; there are individuals, each of whom should know better, given the long history of AIDS education, who continue to conflate the two things. We don’t often hear the suggestion, as we do in Horner’s column, that it is also possible to pay too much attention to the distinction. We see this counterintuitive hint perhaps most clearly in the ironic post-script that he adds to the biographical statement accompanying his contribution: “Oh, and he has AIDS”. A mock throwaway whose third-person voice quite deliberately puts some distance between himself and his AIDS, Horner’s remark could be paraphrased as saying “I’m not going to understate the significance of my current health, but I refuse to let it be the only thing, much less the first thing, that you know or think about me.”. Strictly speaking, AIDS could never simply be an after-thought, something about oneself or about another that you could almost forget and then remember to add in the nick of time. But it is helpful momentarily to stage AIDS as if that were the case, as Horner does in that little addendum: knowing that he has AIDS is critical, yes, if for no other reason than it lets readers understand something about the complicated place from which he speaks. But there are so many other things that are also important about the illness, and Horner wants to ensure that we know that too. So he defers saying that he has AIDS until the end of his remarks, not to evade the question but to call for more complicated and capacious queries from his readers. As we see in different ways in the other columns gathered here, HIV can make people – regardless of their serostatus – acutely aware of their surroundings, and particularly vigilant about how HIV may be understood or misunderstood by others. So it is that

Horner does not begin his column by telling us about his current health status, no more than Barber has simply disclosed at every opportunity that he is HIV+. Each is careful to practice a kind of circumspection about what they say and how they say it, deliberately resisting the imperative simply to disclose, and in doing so each columnist models for others what it means to be at once respectful and thoughtful in the neighborhood of HIV.

“This is positive”, we might say of that particular lesson, remembering the pointed turn of phrase that paces the narrative of Horner’s entire column. Far from a mere slogan, it is a declaration that demands that we sit up and listen, as if hearing a bell tolling in the night. But it is also a promise, and thus a declaration of hope made in earnest of a healthier future, a future less marred by the cruelties and missteps that Horner recalls, and that he asks us not to forget when we tell the story of this epidemic going forward. Given what Horner relays us in his narrative, the fact that there are “positive” signs in the midst of an epidemic is nothing short of miraculous – except to describe it thus would be to elide the suffering, sacrifices, and plain hard work that has brought us by fits and starts to the point that a man like Horner can say “This is positive” and mean it. As with Guenter and Barber, the emphasis is on how HIV has played the role of teacher, but as Horner makes pointedly clear, the lessons learned are not so much naively uplifting and ameliorative as cautiously hopeful and enduringly arduous in nature. One thing Horner is not inclined to do is to sentimentalize HIV as an untrammelled font of wisdom. “Being positive” does not mean here what it can sometimes mean elsewhere, i.e. possessing or being possessed by a cheerful outlook on life, as if a change in one’s attitude towards a problem solved everything. We get no Hallmark card platitudes about HIV/AIDS from Horner, no blithe clichés which would only mean fleeing the realities of illness rather than seeking a way to thrive amid its interminable difficulties. What HIV teaches, and what societal changes have been wrought by AIDS, have been far too hard-won to be treated with anything but this kind of frankness. For as Horner tells us, whatever the future holds, HIV/AIDS has meant surviving a legacy of searing losses: his husband and helpmeet, his livelihood, and his home have all been taken from him; he has lost friends and acquaintances to HIV disease, either to illness or to the irrational fears and misunderstandings with which the epidemic is uniquely burdened. He suffered isolation and injustices both before and after he made his condition known to others. Horner makes the memory of these deprivations feel uncommonly real and pressing to the reader, reminding us that their deleterious effects remain not only woven into the very fabric of his life, but form an ever-present backdrop to the “positives” that he discovers in the midst of the epidemic and describes for us. Grabbing hold of those “positives” is undoubtedly a move in the right direction, but Horner’s

column also ensures that we remember how terribly dear the costs have been in getting us to that hopeful place. In other words, in Horner's experienced hands, the "positives" do not balance out – much less cancel – the "negatives". HIV/AIDS isn't available to that sort of calculus because the losses swirling in its wake remain unaccountable and without the possibility of restitution, an important lesson well worth recalling when we hear talk of an HIV vaccine being around the corner or news of revised downward estimates of the world's HIV/AIDS numbers. Horner is not about balancing the books, or reassuring us that all will be well, but about finding a way to live life and to live, as he says, for the rest of his life.

Perhaps this is what it means to heal, as Guenter says, even if for now a cure seems improbable. Amid these losses, Horner insists that there are "positives," not in spite but precisely because of the sorts of "negatives" that he describes enduring in his own life. Because "negative" remains a grossly inadequate word to describe the death of a loved one to AIDS, "positive" is a word that Horner uses with

implicit caution and only in a larger historical context of love and loss going back twenty-five years. But use it he does, since there is no gainsaying the ways in which the epidemic has spawned a range of activist interventions and politicized movements that are now directly responsible for increased awareness about HIV/AIDS, legislative changes, and better treatment options, as well as the creation of networks of support-groups and service organizations. And there is still a great deal of work to be done. These are "positive" signs, Horner says several times, affirming a reality that should indeed be affirmed, and that is affirmed in a particularly powerful manner by those who have been on the ground, so to speak, during the time that HIV has been with us, the time in which, in consequentially different ways, we have all lived with AIDS. The fact these signs require repeated avowals also puts to us that the avowal itself functions as a kind of talisman or incantation, spoken aloud as if to ward off, for a moment, the heart-break that it also remembers.

We thank our contributors for their candour and courage, and for having taught us so much. †

Author Biographies

David L. Clark teaches students of that generation. He is Professor in the Department of English and Cultural Studies and Associate Member of the Health Studies Program at McMaster University. He has taught courses and supervised graduate research on the social and cultural aspects of HIV/AIDS for many years. His Wisconsin Public Radio interview on representing HIV/AIDS can be found at <http://www.humanities.mcmaster.ca/~dclark/index.html>.

Anna G. Joong is a medical student at McMaster University who recently traveled to Uganda to see first-hand how HIV/AIDS is treated there. She is a member of the first generation of men and women who have never lived in a world without HIV/AIDS.