

Acknowledgments

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Bullets, balance, or both: medicalisation in HIV treatment

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For the past 2 years, I have directed the Understanding Lipids Project, which examines the changing relation between biomedical disciplines at the clinical level, where doctors and nutritionists work to educate and deliver services to HIV-positive people with lipodystrophy and other metabolic side-effects of HIV. In this setting, I have seen clinicians, patients, and consumer advocates caught up in a subtle disciplinary shift; a shift away from a focus on virology and the blasting away of HIV with drugs, towards an approach that includes more medical subspecialties, with endocrinology having a substantial part to play.

In the many hours I have spent observing discussions between doctors and patients about the patients' drugs and their bodies, while working on a project examining the experiences of patients with metabolic complications of HIV drugs, I have seen firsthand the clash of thinking between HIV-positive patients—acculturated to virological thinking after years of undergoing antiretroviral therapy—and the specialist physician responsible for determining the causes of their metabolic disorders, himself acculturated through years of training and practice in his clinical specialty. In interactions between patient and doctor, doctor and drug-company representatives, and endocrinologists and HIV doctors, I have noted how the two medical specialties—HIV care as evolved in the context of research virology, and endocrinology as practiced in the clinical setting—each with its own culture and self-image, compete and collaborate, as they try to balance the problem of viral load (addressed with antiretroviral therapy) with that of disordered blood lipid and glucose concentrations and visible physical changes (addressed with drugs, diet, exercise, and sometimes cosmetic surgery). In the clinical encounters and in educational forums on lipodystrophy I have noted the continuing struggle by patients to make sense of two understandings of their bodies. On one hand, their bodies are battlegrounds, with virology promoting killing the virus as the solution. On the other hand, their

bodies are systems seeking equilibrium between food and exercise, good and bad cholesterol, and bodily compensation for the toxic effects of lifesaving pharmaceutical bullets. Whereas virological solutions are additive—firing stronger bullets when weaker ones fail—endocrinology proposes balance; that is, introducing chemicals only when diet and exercise have failed.

Work on this project has forced me to rethink my assumptions about how medical ideas enter the social world. In my earlier work, I considered competition between medical science subdisciplines¹ and the process of cultivating good patients, through advertising, health promotion, and clinical interaction, to be largely separate processes.² After investigating these views in the clinical setting, I now see clinical encounters, with their continuing negotiation of diagnosis and treatment, as a space in which the uncertainties and disputes in biomedicine and society as a whole are staged and reproduced over time, doctor by doctor and patient by patient.

This is not to suggest that science moves uniformly forward. The history of AIDS has been full of complicated challenges to the internal coherence of science led by activists and patients against biomedicine, but also by practitioners within the emerging specialty of AIDS care, as different research communities struggled to define and explain the emergent syndrome.³ Through the 1980s, a strong coalition formed between people highly identified with their medical diagnosis (people with AIDS) and a class of medical specialists: the AIDS doctors. AIDS doctors, once aligned only with their original speciality, became forcibly interdisciplinary as they absorbed the crucial new knowledge that virology offered for treatment of people with HIV. These AIDS specialists were often unglamorous family physicians, but their broad clinical experience made them more practically interdisciplinary than other specialists. Over time, as AIDS research and treatment embraced virological solutions, so did they. In the intimacy of the newly specialist AIDS doctors' offices, a

new culture emerged. Communication of diagnosis and treatment eventually resulted in a shared worldview between AIDS doctors and people with AIDS, as both adopted notions drawn from the popularisation of virology's way of understanding the human body as the battleground for a war against viruses. A central feature of this worldview is the belief that a bad outside entity (HIV) has invaded the patient's body, and a bullet—or combination of bullets—is needed to target it.

Into this shared culture between doctor and patient, however, arrived a range of unexpected side-effects: not the usual nausea, peripheral neuropathy, or fatigue that, by the early 1990s, were routine for people taking HIV drugs, but a range of metabolic disorders. For long-term survivors, especially those taking advantage of then-new cocktail regimens, the incidence of cardiovascular disease, type 2 diabetes, and lipodystrophy seemed to increase. The mechanisms of these sequelae remained poorly understood because ageing, genetics, and long-term infection with HIV confounded research aimed at identifying the mechanical relation between body, virus, and drugs. This uncertainty and the increased need to refer patients to cardiologists and endocrinologists disrupted the communication patterns that had emerged between AIDS doctors and their HIV-positive patients.

I don't want to overstate my case: AIDS patients have been cast about between disciplines since the beginning of the epidemic. However, the emergence of HIV metabolic disorders and their treatment has been something quite different; first, because early AIDS patients did not expect to—and did not—live longer lives; and second, their interactions with other kinds of specialists did not pretend to offer the holistic full body and full life approach, as endocrinologists later did, for how to live with AIDS.

My work in a specialised HIV metabolic disorders clinic at the beginning of the shift towards routine referral to endocrinologists has afforded me a front-row seat as this history and the cultural difference in style of communications of virology and endocrinology have been played out. In their encounters with virology, patients had learned that the aim was to get to undetectable, described enthusiastically by many patients as zero load. But during the initial consultation with their endocrinologists, patients encountered a new set of issues and goals, including different clinical values. For example, one well informed patient greeted the new numbers with embarrassment—"I'm not familiar with those numbers yet" (unpublished)—and struggled to place these results in the range of lipids values. Few could keep straight the difference between HDL, LDL, and "that other one" (triglycerides). Accustomed to a generally inverse relation between the viral load and their CD4 count, patients were frustrated when the several lipids values changed inconsistently in relation to one another. Even when terminology between doctor and patient became harmonised, it was obvious that patients often did not have an easy understanding of the interrelation between

their bodies' organ systems. One client I observed, for example, referred to himself as coming to the clinic for "the lipodystrophy," but was also worried about his "wind," as he was having trouble during exercise. Registering the patient's hazy understanding of the potential relation between fat redistribution and cardiovascular symptoms, the doctor continued his assessment by asking, "How is your wind?" Despite having shifted from technical language to a vernacular, the doctor then proceeded with a technical discussion of drugs, using their proper names rather than "your heart pills," a discussion the patient followed without difficulty. The idea of treating a problem with a pill was more familiar to this patient than his "fat" and "wind" being two sides of the same coin.

In another example, one 50-year-old patient I observed had almost entirely reframed his understanding of his body to see it as a battleground against the virus. He experienced slight muting of cognitive function, lipodystrophy, and chronic diarrhoea, all of which he believed to be caused by two decades of HIV infection. He complained of tiredness and reported that his HIV doctor had told him to lose weight. He wanted medications for lipodystrophy, but the endocrinologist felt he should lose weight by dieting. During the summer, he lost about 13.6 kg. Unfortunately, he then came down with an illness. In his follow-up at the clinic 6 months later, he reported that he had gained back all the weight, but planned to return to the diet and exercise. As an aside, he noted that the chronic diarrhoea, which he had believed was a side-effect of his HIV drugs, had completely resolved on his diet. "I guess it was getting the proper fibre." Here we see how, as a result of the holistic approach of the endocrinologist, who prioritised changing diet and exercise over drug interventions, the patient reintegrated his body systems instead of seeing himself mainly as a target for antiretroviral therapy.

What happens in the doctor's office entails recruitment of patients into a medical specialty's conceptualisation of the body. But because medical subspecialties differ or are already hybrid, patients are on the front line in reconciling different, even contradictory knowledge. The distance between biomedical specialties that might once have been bridged mainly by researchers and specialised clinicians is now negotiated by the patients themselves, since their knowledge sets expand and intertwine over time. These encounters might be as important as the professional battles between subspecialties, entrenched in their own culture and approach. Physicians must grapple with interdisciplinarity not directly with colleagues, but as a dimension of the clinical encounter itself.

Conflict of interest statement

I declare that I have no conflict of interest.

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