

Expert patients: learning from HIV

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Accepted 20 September 2010

ABSTRACT

The outbreak of HIV in the early 1980s saw widespread activism among patients and community supporters. The author, a young physician in San Francisco at the time, describes how coming of age as a clinician in the midst of this activism affected her concept of the patient–physician relationship. The insistence of a particular patient, Robert, on specifying his treatment goals illustrates that even people with substantial cognitive challenges can participate in their own care in an egalitarian and active manner.

‘The patient is a 32-year-old, previously healthy homosexual man who presented last night to the emergency department with ...’ This opening became a familiar refrain over the 12 months that I served as chief resident in internal medicine at San Francisco General Hospital, July 1980 to June 1981. That year, as the first breakers of what would become the tidal wave of the HIV epidemic washed over San Francisco General Hospital, and the decade that followed, was formative for me as a young physician. I saw scores of young men die. I rode along as basic and clinical researchers identified the causative agent of AIDS, elucidated its epidemiology, explored the pathogenesis and, ultimately developed effective drugs and treatment strategies. And I worked in relationships with patients who were unfamiliar and often uncomfortable.

Although I was at the time a very young physician, I had already learnt to enjoy dispensing my expertise and compassion to trusting, appreciative and deferential patients. But, at the outset of the HIV epidemic, I had no expertise to dole out. Later, as results from clinical trials began to accumulate, and the gay community developed its own resources to support treatment choices, my recommendations were not uncommonly second-guessed and double-checked. The lack of the usual knowledge asymmetry that characterises the physician–patient relationship was compounded by the fact that, as a straight woman, I knew next to nothing about the sexual practices of

my patients and only a little more about their social lives and personal arrangements. Perhaps I might have tried to maintain the traditional stance of benevolent authority if I had thought I could make it work, but my patients knew that I was entirely naïve, and I knew that they knew it. So instead I had to become comfortable with a more egalitarian partnership and accepting of, and even grateful for, those times when a well-informed patient knew more than I did.

A second feature of HIV care in those early years was the overt political dimension of the epidemic and the intrusion of those politics into the relationships of individual patients with their physicians. The fact that the US epidemic was, and still is, associated with stigmatised behaviours and concentrated in marginalised populations led many patients to expect discrimination in their healthcare. The medical establishment, and individual doctors, were regarded with scepticism and outright suspicion. In San Francisco, the major gay paper ran an article about the AIDS Clinical Trial Group trial that demonstrated the benefit of zidovudine with the headline ‘The sacrificial lambs of ACTG 019.’ The idea circulated widely in the African–American community that medical researchers actually caused the HIV epidemic. As the gay community mobilised, organisations such as the AIDS Coalition To Unleash Power encouraged patients to advocate for themselves, sometimes to the point of confrontation. Instead of the trusting and respectful patients I had imagined taking care of, many of mine were angry, contentious and candidly dubious about my motivations.

This recounting of my personal story may seem out of place in a journal focused on quality and safety in healthcare. However, it illustrates a theme that came up in a number of ways at the Cliveden meeting: the importance of patients as ‘front-line workers’ and the enactment of true patient-centred care. Although I was not always comfortable, I have no doubt that I provided better HIV care



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because my patients forced me to acknowledge my ignorance, to respect their expertise, and to work with them as colleagues. Regardless of their specific condition, patients inevitably have knowledge that we health professionals simply cannot possess, both of the circumstances of their individual lives and how our system is working, or not, to enable them to manage, mitigate or prevent problems.

I had a patient who sadly died in 2007. Robert (his real name—I am sure that he would want it used) was a bisexual schizophrenic with HIV, advanced cirrhosis due to hepatitis C, and difficult-to-control diabetes due to his a typical antipsychotic drug, his protease inhibitor or both. He was remarkably charming but significantly cognitively impaired, with a long history of major-league mixed substance abuse exacerbating the deficits associated with his psychiatric illness. I am a devotee of flow sheets in managing my HIV patients and keep them up

scrupulously. This allows me to see at a glance the sequence of regimens a patient has received, the virological response, when resistance testing was obtained, the current CD4, the CD4 nadir—just about everything one needs to know to manage the increasingly complex chemotherapy of HIV. One day, Robert took his flow sheet out of my hands, looked at it briefly and said ‘Why isn’t my CD4 count 400? I want it to be 400. What are you going to do about it?’ This changed my relationship with Robert, and although he ultimately died of his liver disease, we were able to devise a regimen that boosted his CD4. If Robert—compromised in so many physical and cognitive dimensions—could identify an important care outcome and hold me accountable for helping him achieve it, anyone can.

Competing interests None.

Provenance and peer review Not commissioned; externally peer reviewed.