

### **Thucydides, HIV and HCV. About the contemporary**

It could be an unusual mix to put together the greatest Athenian historian, a 30 years old pandemic and hepatitis (mainly HCV infection). But if you have 5 minutes of your time to waste, follow my joke. Because a conceptual link could be found.

I would start with Thucydides. He writes at the beginning of History of the Peloponnesian War: “Thucydides, an Athenian, wrote the history of the war between the Peloponnesians and the Athenians, beginning at the moment that it broke out, and believing that it would be a great war and more worthy of relation than any that had preceded it. This belief was not without its grounds. The preparations of both the combatants were in the last state of perfection; and he could see the rest of the Hellenic race taking sides in the quarrel; those who delayed doing so at once having it in contemplation. Indeed this was the greatest movement yet known in history, not only of the Hellenes, but of a large part of the barbarian world- I had almost said of mankind”.

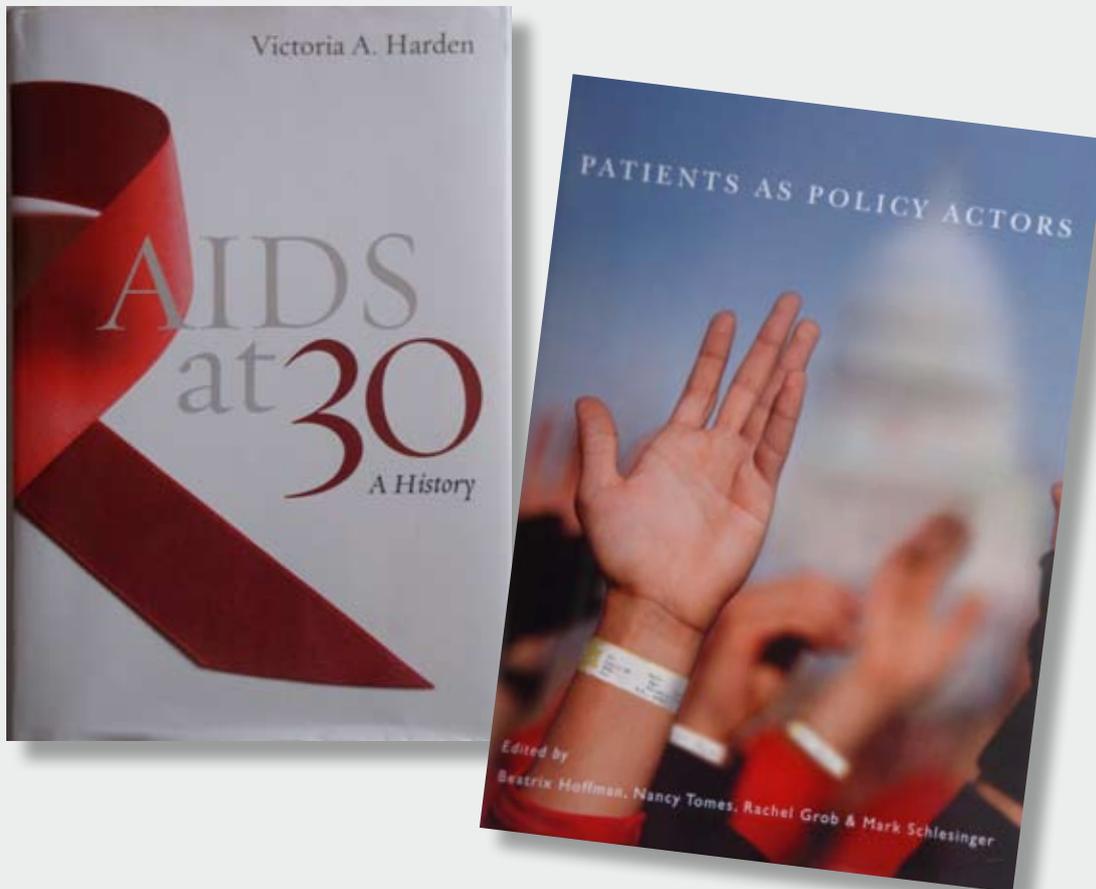
I want to make clear that I have chosen these lines not because of the war metaphor, but because of the issue of time (and also because it is a such impressive start). In this case the key factor relates to the issue of “time” –the innovation made by Tucidides- is how to deal with the distance between an event and its historical description. How long do we have to wait, before we can start to describe, understand and interpretate historical events? Tucidides is the first who gives us an answer. He says that he is “an Athenian” and that he has started to describe, to write, to tell us “the history of the war (...) beginning at the moment that it broke out, and believing that it would be a great war and more worthy of relation than any that had preceded it. This belief was not without its grounds”. Tucidides starts contemporary history, writing as a conscious part of the events he describes -he declares to be “an Athenian”- underlying that he is convinced that the events he was seeing would be “great (...) more worthy of relation than any had preceded them”.

This is what I thought when I received from Amazon my copy of “AIDS at 30. A history” (1), written by Victoria A. Harden. On the backside cover it is written “current events/ medicine/ medical history”. How is it possible to write the history of an event or a social phenomenon that is still going on? It is quite easy to tell when a story starts but how do we know where and where it stops?

For twenty years Victoria A. Harden was funding director of the Office of NIH History at the National Institutes of Health. In her wonderful book she approaches the virus from a multidiscipline perspective in the history of medical science. It enables her to discuss the process of scientific discovery, scientific evidence and how laboratories identified HIV as the cause of AIDS and developed therapeutic intervention. In addition to that, her study defines AIDS as the first infectious disease to be recognized simultaneously worldwide as a single phenomenon (let’s say so impressive as Peloponnesian War seemed to be for Tucidides).

When the epidemic started society was not prepared for the appearance of a new infectious disease. “After years of believing that vaccines and antibiotics would keep deadly epidemics away, researchers, doctors, patients and the public were forced to abandon the arrogant assumption that they had conquered infectious diseases”. AIDS at 30 illustrates “how medicine identifies and evaluates new infectious disease quickly and what political and cultural factors affect the medical community response”.

How do we define an epilogue for AIDS? We can only say where we are now and where we will be –possibly- in the future. When we see the statistics of death caused by HIV, the rates drop drastically after the introduction



of HAART. It happened in 1996 in the northern hemisphere and now we can see a similar trend in the rest of the world. Due to the increase of funding of international donors for diagnosis, treatments and prevention efforts. “Sub-Saharan Africa’s graph shows a similar pattern, with one exception: the number of deaths in the region are measured in millions instead of thousands that characterize the rest of the world”. HIV is a recent discovery: “looking back over the three decades of the HIV/AIDS epidemic, medical science can be proud in how quickly the syndrome was identified, the causative agent found, a diagnostic test prepared and an effective therapy developed”, writes Harden, commenting on Paul Volberding’s quote: “there is probably not anything the equivalent in medicine, apart from maybe the development of penicillin, in terms of night and day difference”.

HIV/AIDS is not a classic epidemic like the 1918-19 influenza or a cholera outbreak: “untreated HIV killed 100 per cent of people who developed full blown epidemic AIDS” and “perhaps the most novel development during the first three decades of the epidemic was the consensus during the third decade that HIV/AIDS required a global response because it was a global threat”. This consensus has made it possible to define a new medical discipline called implementation science: “the scientific study of methods to promote the integration of research findings and evidence based intervention into health care policy and practice and hence to improve the quality

and effectiveness of health services and care”, according to Peter Piot’s definition.

In my opinion this is the best value of this book, written simultaneously when the events and the consequences are happening contemporarily in front of us, it is like a journey in a new land and the author-traveler is mapping the land where we are. I think that Victoria A. Harden rooted its cultural and historical analysis of HIV/AIDS in the same way that Paul Theroux –the acclaimed author of travel books- did. He explains that “in a sense, the world was once blank. And reason cartography made it visible and glowing with detail was because man believed, and rightly, that maps are a legacy that allows other men and future generations to communicate and trade”(2). Speaking about contemporary history, we can say that only time will provide the necessary perspective. Harden suggests that HIV/AIDS epidemic “will be viewed as all others epidemics, as a biological event occurring in a historical time within human social, political, religious and cultural institution”.

In this light, inside our issue of HAART, we decided to cover the Washington International AIDS Conference publishing the opening speech made by Jim Yong Kim, World Bank Group President, about AIDS and poverty, followed by the closing remark made by Francoise Barre-Sinoussi, Nobel laureate and President of International AIDS Society, drawing a possible future scenario from her point of view, being a scientist, a woman and an advocate. In her book Harden claims that “one of the unique characteristic of the HIV/AIDS epidemic has been the vigorous and continuous involvement of people with HIV/AIDS and their supporters, together known colloquially as “AIDS activists”.

It is a curious coincidence that in the same box from Amazon came, with “AIDS at 30”, another book: “Patients as Policy Actors” edited by Beatrix Hoffman; Nancy Tomes, Rachel Grob and Mark Schlesinger (3). The structure of this strong volume reflects the authors’ determination “to broaden conceptions of patients action and to appreciate the complexity of its influence”.

The book is articulated in 3 sections, each focused on a different type of patient action and voice in health care system. Part 1, titled “Voices of the Silent” examines patients who have been silent or silenced and reflects on the implication of their silence, including the efforts of others to speak for them. Part 2, titled “From Individual to Collective”, looks at patients who speak more directly on their own behalf, both as individuals and as groups (could individuals and collective identities shape patient’s roles as policy actors? Can patients voices constitute a collective action? In which way?). Part 3, “How Patient Matter”, explores situations in which patient influence, both intended and unexpected, succeeded in changing policy. This section is closed by Steven Epstein (4), providing “a wide-ranging examination of what it means to say that a social movement has achieved success”.

According with the editors, “the desire to understand the role that patients do, can and should have in health care policy making is the driving force behind this book”. Two considerations support this book: first, putting together researcher from different disciplines –those who are studying in patients empowerment and those who are analyzing health care system- the book constitutes an excellent opportunity to pool the different authors/ disciplines insights “into the complex ways that patients interact with health care institutions and influence policy outcomes”. Secondly, it represents the more complete state-of -the-art volume on “wide variety of patients actions and policy arenas”, preferring to use a broader definition of an action in order to represent more accurately “the impact and the potential of the patient-consumer voice in the health care system”. The proposed analysis starts from the fact that “two paradigms – patient-centered medicine and consumer-driven health care- have emerged

as road maps to define how patients should exercise greater control over their care” wrote Nancy Thomas and Beatrix Hoffman. “Patient-centered medicine attempts to enhance patients’ involvement in clinical decision making, while consumer-driven health care focuses on economic choice”.

In different ways, but “both paradigms assume that consumers empowered to act on their needs and preferences will change the health care system for better”. Where is the contradiction? Although both approaches have drawn new attention to the role that empowered patient can play in restructuring a dysfunctional health care system, they tend to put the cart before the horse: they assume that a patient can have a corrective influence on health care trends in the absence of concrete evidence that such a capacity exist”. There are not many in depth analysis that investigate if and how patients and consumers could play a role in transforming doctor-patient relationship, medical institutions, access to care, health care policy. “Although patient initiative have secured the expansion of some kind of choice and safeguards, especially for the educated and affluent, they have been offset by growing demands for costs containment and marked discipline that have limited both physicians’ and patients’ autonomy”.

In the book there many pages devoted to Hepatitis, but what is happening in our world in these days –let say in the contemporary- with the revolution of Direct Antiviral Agents (DAAs) for HCV infection, create the perfect scenario to read the “Patients as Policy Actors”. Access to drugs, prescription criteria, reimbursement, cost-containment and budget constraint are the key words through which Scientific Societies, health care providers, patients associations and decision makers must define the best inclusive public policy to respond to health needs. This is the reason why we publish in this book the expert opinion on DAAs by AISF –the most authoritative Italian scientific society on liver disease- and a comment from a member of this society, prof. Calogero Cammà. This is just the beginning of a debate on DAAs. In the next HAART issue we will host other comments from MDs as well as from patient associations. We will welcome any further comments...

I wish you a pleasant reading.

Andrea Tomasini

- (1) Victoria A. Harden, “AIDS at 30. A History”, Potomac Books, Washington, 2012
- (2) Paul Theroux, “Mapping the World”, in “Sunrise with Seamonsters”, Houghtin Mifflin Company, Boston-New-York, 1985
- (3) Beatrix Hoffman, Nancy Tomes, Rachel Grob & Mark Schlesinger Eds.” Patients as Policy Actors”, Rutgers University Press, New Brunswick, 2011
- (4) Steven Epstein, “Measuring Success. Scientific, Institutional, and Cultural Effects of Patient Advocacy” in “Patient as policy Actors”.