Therapeutic Sovereignty: HIV/AIDS and the politics of survival in West Africa

FAHDILA MAZANDERANI
School of Applied Social Sciences, Durham University


Since the Centre of Disease Control (CDC; now the Centre of Disease Control and Prevention) in Atlanta started issuing reports on the emergence of strange cases of Kaposi’s sarcoma and pneumocystis carinii pneumonia (PCP) in otherwise healthy young men in 1981, the syndrome that would go on to become known as AIDS has been extensively studied by the biomedical and social sciences. Over the past thirty years social science research on HIV/AIDS has changed rapidly, responding to the shifting demographics of the epidemic, high levels of patient activism and the emergence of antiretroviral medication as a viable treatment for the virus. Despite these changes, the question posed by the cultural historian Paula Treichler (1999) in the title of her collection of critical essays on the cultural significance of HIV/AIDS – How to have theory in an epidemic? – still remains very relevant today.

While there is no straightforward ‘answer’ to this question, it is one with which, in different incarnations, many social scientists working in the field of biomedicine grapple. Eleven years after the publication of Treichler’s Cultural Chronicle of AIDS, medical anthropologist and HIV physician Vinh-Kim Nguyen provides in his The Republic of Therapy one version of what such theorising might look like. Like Treichler, Nguyen does so in the context of HIV/AIDS; yet the epidemic he is dealing with is strikingly different to the one described by Treichler. Situated in Burkina Faso and Côte d’Ivoire, rather than North America and Western Europe, and focusing on the period between 1994 and 2000, when antiretroviral (ARV) drugs first started to become available, Nguyen offers an engrossing and at times troubling ethnography of the changing dynamics of HIV treatment and care in West Africa.

The Republic of Therapy is not only a very readable book, combining a historical narrative with insights garnered through ethnographic experience, it is in many ways, a brave one. For, with the dramatic success of Highly Active Antiretroviral Treatment (HAART) in providing a treatment, but not a cure, for HIV, a huge emphasis has been placed on making the drugs available to those that need them. The very real urgency of this endeavour has meant that critiquing the ways in which it has been carried out and the consequences it has for the lives of different people and countries is far from an easy task. Nguyen manages to provide such a critique in a manner that is both incisive and sensitive.

A key aspect of this work is that it focuses on a field so fraught with economic and political instability that, paradoxically, being diagnosed with a potentially fatal virus may be the only way in which people can attain some level of material support. Thus, at heart, the book can be read as an extended inquiry into the question posed on page six: ‘what forms of politics might emerge in a world where sometimes the only way to survive is to have a fatal illness?’ And...
the response Nguyen develops in order to answer this is the notion of ‘therapeutic sovereignty’ – a novel form of political power, emerging in post-colonial contexts where widespread poverty and political instability result in the absence and/or failure of more ‘traditional’ forms of sovereignty (p.133-134). The notion of ‘therapeutic sovereignty’ that Nguyen proposes is a multi-faceted concept, the strength of which emerges through the interactions of ‘therapeutic citizenship’, ‘triage’, and ‘confessional technologies’.

Building on the concept of ‘biological citizenship’, developed by Adriana Petryna (2002) in relation to Chernobyl, and then extended by Carlos Novas and Nikolas Rose (2005) in relation to the rise of the ‘new genetics’, Nguyen proposes the notion of ‘therapeutic citizenship’ to describe the ‘thin’ forms of citizenship that emerge from a focus on the treatment of one particular disease or condition (in this case HIV), in contexts where large stable governments and healthcare institutions are absent (p.109). It is in these circumstances that the aforementioned paradox arises when access to some of the material security one typically associates with other forms of citizenship only becomes available to those diagnosed with HIV through ‘therapeutic citizenship’.

Nguyen traces the genealogy of the ‘therapeutic citizenship’ he encountered in West Africa to participation in clinical trials in the early years of the epidemic in North America, Europe and Australia in which the search for a cure was a highly political activity (p.91-93). In particular, he argues that in the mid-1990s as large trials on mother to child transmission were being conducted in Africa (including two in West Africa) increasing numbers of women were made aware of their HIV positive status and the possibility of treatment, yet were in many cases excluded from participating in trials (due to medical or other reasons) and left unable to access life-saving drugs (p.93-95). This resulted in the formation of support networks and activities centred on gaining access to treatment. While these activities were political in that they were ‘rights’ focused, they differed from the political mobilisations of North America and Western Europe: they were shaped by poverty and lack of social and state support, rather than gay rights and a sense of solidarity with people affected by HIV. Thus, as NGOs and others started to facilitate access to treatment, they became conduits for material support in the form of financial aid, education, general health care, and, in some cases, even supplying identity documentation typically provided by governments, in order to provide treatment. Yet simply being diagnosed with (or indeed claiming to be diagnosed with) HIV, did not in itself open up access to this form of therapy-centric citizenship. For in contexts where healthcare resources are scarce, such as in much of Africa, different forms of ‘triage’ operate.

Triage is a medical term adopted from emergency medicine that describes the ways in which decisions are made regarding who receives what treatment and when (p.10). While triage is a well-known and accepted medical practice, what makes Nguyen’s use of it so original is the way in which he draws attention to the types of processes and information that get enrolled in the decisions as to who receives the lifesaving HIV drugs that find their way to West Africa. Chief amongst these is what, drawing on the work of Nancy Hunt (1997), he conceptualises as ‘confessional technologies’. These represent a collection of practices and techniques centred on disclosure and narrative, which are used in a context where ‘being able to talk about oneself became a matter of life and death’ (p.87).
Chapter Two, ‘Confessional Technologies: Conjuring the Self’, in which Nguyen follows various ‘talking technologies’, from phone lines and support groups in North America and Europe to West Africa, is one of the most compelling in the book. Here he argues that these technologies, premised on particular cultures of empowerment and self-help that emerged in the wake of the North American and European AIDS epidemic, are creating new forms of (not always cohesive) community and self-fashioning. The analysis presented in this chapter is not only relevant to the field of HIV/AIDS, in which patient testimonials and narratives are ubiquitous, but addresses issues with wide-ranging significance for the use of narrative and storytelling as modes of ‘empowerment’ in contemporary health care more generally. Although the case Nguyen explores is a particularly striking one, insofar as ‘talking about yourself came to be about staying alive’ (p.9), his analysis goes beyond this and opens up much needed avenues for more in-depth explorations of other ‘talking technologies’, many of which play a key role in the activities of social scientists.

Theoretically, Nguyen draws heavily and productively on Foucault, invoking biopower, governmentality and technologies of the self as key structuring devices in his own thinking. However, some of the most interesting insights offered by the book emerge from careful and sensitive adaptations of the Foucauldian line of argument to the case-study in point. One example of this is Nguyen’s development of the concept of ‘nongovernment’ biopower ‘that disseminates through a patchwork of international organizations and community groups’ that lie outside of direct state control (p.113). Another is the linking of the transformative dimensions of technologies of the self specifically to ‘survival’ and, in particular, to the pursuit of economic and other material benefits, such as gaining access to medication, travelling abroad or purchasing a car (p.156). Interestingly, one of the main critiques of the role out of ARVs in ‘resource poor’ settings is that medication alone is not enough. For people to fully benefit from HIV-treatment they also need access to primary health care facilities, sufficient food, proper housing and so on. In the case of the select ‘therapeutic pioneers’ that Nguygen studies, this situation is reversed – it is precisely through vocalising their experiences of HIV and sometimes even becoming the spokespeople of international organisations (often at risk to themselves due to persistently high levels of stigma) that these individuals gain access to basic forms of material support that can in turn enhance the efficacy of their HIV-treatment. Such insights and experiences can have wide-ranging significance for people working in the context of NGO-provided health care and the increased roll-out of ARV treatment programmes. Unfortunately, Nguyen does not expand on what he thinks the practical implications of his work might be, and further explicit discussion both on his original theoretical insights and their implications for policy and practice would have been welcome.

Although well informed by theory, The Republic of Therapy is not overladen with it and the engaging and impassioned narrative voice of the author more than compensates for a tendency towards repetition. One of the book’s key strengths lies in the eclectic range of material, metaphor and imagery that Nguyen draws on. Moving from ‘medical’ concepts such as triage to ‘social’ ones such as ‘technologies of the self’, Nguyen avoids reifying or polarising the social and the medical as two separate entities. Furthermore, in the context of post-colonial studies of public health, Nguyen draws attention to the significance of the colonial legacy without reducing his analysis to an overly simplistic critique of it, highlighting the fluid and constantly changing relationship between what counts as
‘indigenous’ culture and ‘external’ forces. That said, while the more ‘historical’ portions of the book provide necessary background, Nguyen is at his strongest when analysing firsthand ethnographic accounts and drawing on his personal experiences as an activist and physician.

Social studies of HIV/AIDS have been productive sources of theory, resulting in work ranging from Emily Martin’s analysis of the significance of notions of ‘immunity’ in American culture (Martin, 1995) to Steve Epstein’s seminal work on AIDS activism and the politics of knowledge (Epstein, 1996). Post the success of ARVS as a treatment, but not a cure for HIV, social science researchers are faced with developing and answering new and evolving questions in order to grapple with the shifting dynamics of the epidemic. With this book, Nguyen joins other notable scholars working in the field of HIV/AIDS (Biehl, 2007; Rosengarten, 2009) in asking how to have theory in an epidemic for which treatment is becoming increasingly, yet not universally, available. Moreover, he does so through foregrounding the role that storytelling plays not only in documenting the epidemic, but in shaping it. As governments across the African continent ramp up their roll-out of ARV medication, work such as Nguyen’s serves to remind us of the profoundly social nature of medicine in an epidemic turned chronic.

References


BIO:
Fadhila Mazanderani is Lecturer in Sociology at Durham University. Prior to joining Durham, she was Research Fellow at Warwick Medical School, University of Warwick. She completed her DPhil at the University of Oxford where her thesis focused on the use of internet technologies in contemporary HIV care. She is currently working on a project investigating the production and dissemination of ‘experiential knowledge’ in the context of neurodegenerative illness.