

Comments by Alan Brotherton

Delivered at launch of new book: *HIV Interventions: Biomedicine and the Traffic between Information and Flesh*, by Marsha Rosengarten

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I want to put these comments in some sort of context for you - and to help clarify from what position I'm speaking - by sharing with you that I have lived with HIV for 24 years. Many people, kindly, reflect this back to me as some sort of personal achievement - but whether or not that's the case, for me the important point in relation to the content of Marsha's book is that it's a sad indictment that 24 years is still 2 or 3 times as long as the majority of people who will be diagnosed with HIV this year will get to live.

I read Marsha's book with great interest, and I have to confess, with inconsistent adherence and only partial comprehension. As Ursula Le Guin once wrote about the French philosopher Gaston Bachelard "I do not always fully understand Mr Bachelard, but when I do or when I believe I do, then I want to follow with drums and a marching band".

So even amongst the luxuriant thickets of poststructural theory which cover the slopes of chapter 2 - Marsha warned me it was a difficult traverse - I came across small clearings and beams of light which opened up new insights on aspects of our work which I realise that I, and many of my colleagues working on HIV, have come to take the granted and where we have ceased to question our assumptions. I just want to mention two of those now.

The first is the way in which the medical technologies which allow us to monitor the impact and progress of HIV in our bodies have changed the way in which we think about and imagine HIV, and how they have transformed our lived experience as people with HIV. Prior to the advent of the viral load test I would attend my doctor's surgery regularly to look at a number of bio markers which we presumed gave us some kind of picture of what the virus was doing. The model with which we worked was one of a latent virus whose latency could be measured in some degree by the overall health of the immune system as indicated by CD4 counts. For a while there, there was also some interest in CD8 cells and other immune new system components but I don't think it ever became entirely clear what their predictive value was.

Nonetheless, it made sense to keep track of the state of the bodily function which it was presumed the virus could eventually destroy, if something caused it to emerge from its latent period. There was also, I recall routine monitoring of the P 24 surface antigen. I no longer recall quite why this is important or what it was although it was understood to indicate some potential for disease progression. At any rate, the overall impression I retain of the virus at that time was of an unpredictable, labile cohabitant, but harmless enough until something caused it to wake from its latent state. In my own mind I engaged in a form of bargaining along the lines of 'it's in your interest to allow me to continue to live as a host and as long as you show some restraint I'm sure I can provide you with a comfortable long-term home'.

Most significantly, the measure of my 'wellness' in which my doctor was most interested was how well I felt in myself.

All this changed with the advent of the viral load test and new insights into viral dynamics and the natural history of HIV disease. All of a sudden, the virus transformed from something with which one could peacefully coexist - often spoken about and therefore materialised in the singular -- to a teeming host seeking constantly to replicate and to pervade all corners of the body from where it could always emerge to overrun the system -- a view which eerily foreshadows subsequent US foreign policy and Australian immigration policy under the Howard government.

David Ho's pronouncement that "it's the virus, stupid" became the new battlecry of an all-out assault on viral replication. As someone who initially was unable to achieve full viral suppression but who nonetheless witnessed consistent increases in CD four count, I was relieved some years later when the importance of immune function was restored to the pedestal as the ultimate goal of viral suppression.

Nonetheless, there remain troubling tensions in the debate around viral suppression versus immune reconstitution and what this means for the health and well-being for people with HIV, tensions which play out around and behind the ongoing debates about treatment as prevention.

The second issue I found myself dwelling on is the is the issue of treatment side-effects and the ways in which clinical information regarding the impact of treatments materialises a population of 'well' patients, often in contrast to the lived experience of those of us actually taking the drugs. I am deeply grateful to the many years of extra life and relative well-being which treatments have brought me and also humbled and dismayed by the realisation of the extent of the privilege that this

opportunity constitutes. Nonetheless, the first few combinations produced a series of at times, comically extreme side-effects, including at one point the loss of all body hair, at another random attacks of elation and anxiety and a spectacularly purple rash in honour of which I have chosen tonight's shirt.

The side-effect of most significance - and one which led to a remarkable proliferation of conversations about bowel habits and an even more intense interest in the location of public toilets than had been the case to date even amongst Sydney's gay male population – was, of course diarrhoea. Whilst this was produced in clinical discourse as a common but manageable side-effect it manifested in our lives as a daily source of anxiety, discomfort and sometimes shameful public humiliation.

New treatments have vastly improved the situation of those of us with the privilege of access to them. Nonetheless, the majority of people with HIV on treatments today, who have only limited access to this first generation drugs at best, still have to contend with these treatment effects and in situations where the resources to manage the physical and social impacts are drastically limited in comparison to those available to us in the global North 10 years ago.

I'm following this line because of an event that occurred shortly after I began reading Marsha's book, whilst travelling in India. Our train was stopped just outside a large city. I looked up from the book to see someone squatting on the railway embankments, out of sight of the houses among which she presumably lived, but in full view of the Lashkar express. I and the other passengers pulled close the curtains, I would like to think in order to reduce the shame felt should she turn

around to realise the stationary train behind her. That leads me to a tangential thought about the power of the averted gaze in the face of another's presumed shame and its negative effects on the capacity of so many countries to deal with the needs of those most affected by HIV.

That however is another point for discussion elsewhere. But the point this incident most starkly raised for me was to contemplate the impact of first-generation ARV on someone with HIV living in this situation. The capacity we enjoyed to manage, suppress and diminish the social impact of these side-effects is simply not available to so many currently taking the same drugs - with a presumably devastating impact on their confidentiality, self-esteem and social capital.

In the book, Marcia produces an excellent account of the way in which the term 'treatments complacency' has been wielded to condemn the behavioural adaptations of gay men to the prevention possibilities of antiretroviral treatment. I would argue that there is another form of treatments complacency, in which the HIV sector as a whole engages to a greater or lesser degree.

We regularly hear triumphal talk of treatment rollout and increased ART coverage as a 'success', a task done, and in doing so we often materialise those people with HIV who have access to treatment as physically well bodies, a problem solved and one which allows us to move on with the task of getting more people on treatment. This is, of course, a good and laudable aim and I'm not for a moment arguing we shouldn't continue to push for full treatment access for those who need it with all the energy we can muster.

However, as Marsha so eloquently reminds us, we must take time to reflect on what we are doing, on our assumptions and of the real effects of our actions on the bodies and lives of those who are the intended beneficiaries – otherwise we run the risk of discursively marginalising as incidental side effects, a set of real effects with significant social and material consequences.

So, despite my perceived struggles with post structural theory I've emerged from reading 'HIV Interventions' with fresh thinking on familiar topics, and a heightened awareness of the ethical minefields over which we tread so casually in our daily work. I think that's what we call a bracing and refreshing read – so, thank you Marsha, and I look forward to engaging further on these vital topics.