The biopolitics of engagement and the HIV cascade of care: a synthesis of the literature on patient citizenship and antiretroviral therapy

Sara Paparini\textsuperscript{ab} and Tim Rhodes\textsuperscript{ab}

\textsuperscript{a}Faculty of Public Health Policy, Department of Social and Environmental Health Research, London School of Hygiene and Tropical Medicine, London, UK; \textsuperscript{b}National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Blood Borne and Sexually Transmitted Infections, University of College London, London, UK

\textbf{Abstract}

The 'cascade of care' construct is increasingly used in public health to map the trajectory of local HIV epidemics and of different HIV populations. The notion of 'patient engagement' is key to the progress of people living with HIV through the various 'steps' of the cascade as currently conceptualised. The public health literature on the definition, measurement and interpretation of cascade of care frameworks is growing in parallel with critical social science literature analysing patient engagement through the lenses of 'patient citizenship' theories. In this paper, we review qualitative literature on HIV treatment, adherence to antiretroviral therapy and care engagement that draws upon the interlinked concepts of therapeutic and biological citizenship. We aim to offer a critique of the cascade of care construct using empirical data from research studies published since 2005 that were influenced by these two concepts. In so doing, the paper places public health literature on the cascade of care in dialogue with in-depth qualitative and ethnographic approaches, to unpack the understandings and processes shaping patient engagement in HIV treatment and care in different settings. The paper also examines the contributions and limitations of the concepts of biological and therapeutic citizenship as argued by a number of scholars here reviewed.

\textbf{Introduction}

The HIV treatment 'cascade of care' envisages 'treated HIV' as the end point of a process of sequential care engagements – from HIV testing, to diagnosis, to linkage and access to antiretroviral treatment (ART), to retention in treatment – sufficient to bring about viral suppression (Mugavero, Amico, Horn, & Thompson, 2013). The cascade creates a framework for generating stepwise estimates of intervention access, coverage, adherence, retention and outcome at national and regional level (Kozak, Zinska, Leeper, Willig, & Mugavero, 2013; MacCarthy et al., 2015). Such a framework provides an overview of key indicators (diagnosed and undiagnosed infections; numbers on or off treatment) and their public health implications and offers a surveillance grid for monitoring patient disengagement through the pathways of care. The cascade construct thus tends to define HIV care (and its success or failure) narrowly in relation to the ultimate benchmark of viral suppression, resulting from patients being sufficiently and appropriately engaged through each of its steps.
A practice-based approach

Enables us to examine and explain how context, whether social, bodily, temporal, historical, cultural, geopolitical, economic, relational and so on, shapes daily practices.

Three features of practice (Blue et al 2016)

1. Practice depends on the ongoing integration of basic building blocks (material, competence, meaning).
2. Practices do not exist in isolation. There are connections between them, competition and collaboration.
3. Practices are dynamic. People float in and out of practices through processes of recruitment, maintenance or defection.
Building blocks

i. **Materials** - The availability of drugs, nutritious foods, accessible and responsive health services, assets and economic resources.

ii. **Competence** – Know how/able to... adopt a patient persona/therapeutic citizenship, accept HIV status, live positively.

iii. **Meanings** – Bodily and historical experiences of ART, forms of masculinity, perceptions of health services, normalisation of HIV, AIDS no longer a death sentence, stigma and discrimination, social norms.
Competition and collaboration

- The practice of cascade engagement is facilitated by a ‘bundle of practices’, e.g., accepting or denying HIV status, disclosing HIV status, relationship building with health providers, participating in support groups, living positively, taking drugs.

- These practices (in the project ‘staying alive and healthy’) were in harmony or conflict with other practices, e.g., being a parent, spouse, enacting masculinity.

- Practices shared or competed for resources, e.g., prioritise food for the family over self, therapeutic pluralism.

- The trajectory of one practice may shape the trajectories of others, e.g., denial or acceptance of HIV status.
Recruitment, maintenance or defection

The chances of joining or remaining on the treatment cascade, depend on ...

... what the practice itself demands
   Treatment made easy and accessible, not disruptive to other social practices

... previous life histories
   Bodily experiences, knowing someone who has died from AIDS, or is on ART

... resources/building blocks
   Materials, competencies, meanings

... various actors
   Health care providers, support groups, treatment partners / supportive family, PLHIV themselves, churches and faith healers, traditional healers
Beatrice, age 54, Zimbabwe

2008. I got tested and was found to be positive. I came on my own because my husband had died and I thought I was infected. I was put on cotromoxizole. I used them for many years.

2014. I was finally given ARVs. I stopped taking them after only a few months. My face, hands and legs started swelling. Then they started peeling and my face became black.

The doctor did not tell me anything satisfying. He told me to continue taking the ARVs, which I did and the reactions started again. I stopped. I started. I stopped.

My health was deteriorating and I was not in a position to support my family. I am both the mother and father so I decided to stop.

The nurse once called me enquiring why I was no longer coming to ART clinic and I told her my worries that they have been unable to explain to me why my body was peeling. I have not experienced any health problems up until now.
Conclusion

• Cascade engagement must be positioned within a constellation of practices at local level, many of which will not 'shift' to accommodate what is needed to perform patient engagement.

• Standardised expectations of patient engagement in the cascade, if not negotiated amongst other practices locally and not only individually, can run counter to its actualisation.

• Future research ought to focus on the configuration of elements that facilitate cascade engagement.
Stigma temporalities & the HIV treatment cascade

Dr Oliver Bonnington

With: Joyce Wamoyi, Dominic Bukenya, Morten Skovdal, William Ddaaki, Robert Ssekubugu, Estelle McLean, Jenny Renju, Alison Wringe & the Bottlenecks team

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Three overlapping stigma temporalities

Derived from Hartmut Rosa’s three temporal perspectives:

- Everyday life – stigma within daily routines and repetitive dilemmas
- Biographical time – salience of stigma in relation to life plans and projects
- Epochal time – stigma in the structured rhythms of our time
Stigma within Everyday Life

• Rakai, Uganda:
  “There are some who turn back [from the clinic] when they find someone from their village who knows them. They don’t get tested because they are in fear of being seen.” Counsellor

• Masaka, Uganda:
  “Some of them [friends] rumour monger. When they happen to hear of something, they go on spreading it” Crisis ART initiator
  “I hide my drugs. No other person is aware that I am taking HIV treatment except my partner” ART 6-12months non pregnant

• Manicaland, Zimbabwe:
  “After the test I was told that I have the virus and I accepted it. I went back home and when we were bathing in the rivers I was sickly and they laughed at me. You see. This made me to stop the treatment. I stopped the treatment for three months, I was very depressed and fell ill.” PLHIV-ON-ART-GEN IDI-3

• Kisesa, Tanzania:
  “How will [neighbours] regard me being in the queue there, on the bench waiting for the medicines or when I’ve gone for testing... how will they think of me?” IDI#13
Stigma within Biographical Time

• Rakai, Uganda:
  “If you had no man, you wouldn’t get anyone [if they knew your status]. If someone loved you, [friends] would say to them, ‘that one is sick’” Stable Non RHSP

• Masaka, Uganda:
  “I fear that someone might spread it to other people and my partner gets to know about it” Recent ART Initiator

• Karonga, Malawi
  “We old people tend to mix with children there [hospital]. So other people tend to think about how we old people got infected with this disease.” Male, 40+, On ART

• Manicaland, Zimbabwe:
  “If I know that John is HIV Positive we start to laugh at him and when Susan tells me that John is interested in her I will tell her that she is going to die” On ART

• Kisesa, Tanzania:
  “Younger people still have the element of secrecy... so ... they stop using medication” Healthcare Provider
  “After further encouragement, her family members visited, they refused to be supportive and started to divide the old woman’s possessions as she watched... They told her they will stay distant until she passes away then take her remaining possessions.” Healthcare Provider
Stigma within Epochal Time

• Rakai, Uganda:
  Q/ Did you test together with your husband?
  A/ No, he does not allow, he does not accept. He does not tell me. I got this feeling that he is like me [HIV+] but fears to tell me.” Diagnosed, not in care

• Masaka, Uganda:
  “Church leaders, like priests and catechists, preached against community stigma in their communities” Healthcare worker
  “We mixed HIV patients with general ones because of stigma. Patients were afraid of being seen coming from the counselling room” Healthcare worker

• Karonga, Malawi:
  “Currently, there is no stigma.” Healthcare worker

• Manicaland, Zimbabwe:
  “We were recently called to a community court in a case in which a grandmother was emotionally abusing her daughter-in-law for her status. I took the matter as my own and told her to bring the person who disclosed the status to her and take it further to the police. She brought the person who had told her but the person refused. The daughter-in-law is still being emotionally abused. Ok so we continue to counsel her.” Recent ART Initiator
  “Each household where there is person living with HIV, those people accept it, they understand now. But where there is no one with HIV they see it as a joke.” Diagnosed, not on ART

• Kisesa, Tanzania:
  “Now, people are no longer stigmatised like in the past” Healthcare Provider
  “I just felt normal about having [AIDS], like it was a normal thing because it’s not just me who has it... why would I be shocked? It has become a disease for everyone.”
  “He has already taken the test and he realises that he is infected. Then he will take the drugs and his health will get back to normal. Once he has become normal then he starts to take those women that are not infected, he spreads it to them, now he thinks it is a normal issue.”
Key Points

• Temporalities of stigma can disrupt the treatment cascade at all ‘stages’
• Everyday gossip has intense effects (even if there are some signs of epochal shifts to greater inclusivity in the age of ART)
• Less marginalisation and fear of stigma in Manicaland compared to Kisesa, Karonga, Rakai and Masaka?
• HIV stigma seen through socio-biographical time is difficult to eliminate
• Epochal obstacles: Persistence of patriarchy (men not willing to disclose, dropping out, in control and intransigent), low and intermittent medical resources, few community-level anti-stigma programmes, ambivalent role of ART, to separate or to mix patients at clinics?