Eddies, backflows and stagnancy: The HIV Treatment Cascade and its 'Goodness of Fit'

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ALPHA NETWORK
Analysing Longitudinal Population-based HIV/AIDS data on Africa

Introduction

The HIV treatment cascade has become a guiding model for delivering medical HIV services, focusing on sequential steps, from the initial diagnosis of HIV through to viral suppression. Although the cascade has helped to standardize measures of care and delivery of HIV treatment at an unprecedented scale, prolonging the lives of millions of people [1], a large proportion of unexpected deaths still occur throughout the cascade [2-4]. The ALPHA Network has found that this is partly explained by varied engagement with the treatment continuum, with persons living with HIV stepping in and out of HIV services in multiple and unpredictable ways, leading to different forms of disruption to progression along the cascade, or what we call eddies, backflows and stagnancy.

How can we explain varied engagement with the treatment cascade? What is the 'goodness of fit' between the treatment cascade and the lived realities of people living with HIV?

Methods

Data were drawn from a multi-country study conducted by the ALPHA network, examining how people living with HIV, and their sociality, interact with the HIV treatment cascade. Studies took place in Uganda, South Africa, Malawi and Zimbabwe (see Fig. 1) and involved in-depth interviews with 38 HIV service providers, 196 people living with HIV and 23 relatives of people who have died from AIDS-related illnesses. See Table 1 for a breakdown. Ethical clearance was obtained in each country. Data were coded in NVivo10 using inductive and deductive approaches to identify emerging themes.

	Malawi	Zimbabwe	South Africa	Uganda	Total
Health care workers	5	4	18	11	38
Diagnosed but not initiated	9	13	10	24	56
Recently initiated on ART	7	15	10	16	48
On ART long term	20	20	7	14	61
No longer in care	4	11	6	10	31
Relatives	6	3	6	8	23

Table 1 Number of interviews with study participants across country sites

Fig. 1 Health and demographic surveillance **s**tudy sites

Conceptual framework

This paper adopts a *practice* approach [cf. 5] to examine the interplay between the diverse lived realities of persons living with HIV and their varied engagement with, and experiences of, the treatment cascade. Seeing 'cascade engagement' as a practice, offers a unique opportunity to unpack:

Theories of practice is an approach for examining and explaining how contexts, whether social, bodily, temporal, historical, cultural, geopolitical, economic, relational and so on, shape daily practices and lived experiences.

1. How cascade engagements are constituted and enacted by multiple elements and not just people alone; and
2. How cascade engagements relate to other everyday practices across space and time, exploring the role of competing and collaborating practices, and
3. How these in turn are shaped by social, relational, discursive, cultural, economic and political forces.

By unpacking the 'background of practices' we can understand how different social practices, processes and lived experiences contribute to eddies, backflows and stagnancy in people's engagement with the HIV treatment cascade.

Results

"The government is emphasizing a lot that everybody should use ARVs, but people who started ARVs from some time back, don't they die? […] if it's time for somebody to die, its time and nobody can escape death." Eligible male not enrolled, Malawi

"2014. I was finally given ARVs. My face, hands and legs started swelling. 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." Eligible female drop out of care, Zimbabwe

These examples show how attitudes to life and ART, as well as the demands of other social practices (e.g., parenting, coping with side-effects, generating food, making a living), prevent some people from seamlessly flowing through the cascade. Other factors identified in the study are depicted in Fig. 2.

1. Elements affecting cascade engagement

Meanings e.g. bodily and historical experiences (side-effects being worse than risk of stopping ART); forms of masculinity; stigma; medicalisation of treatment; ART readiness; normalisation of HIV; perceptions of health services; AIDS no longer a death sentence; perceptions of ART and their effectiveness.

Materials e.g. drug and food availability; accessible and responsive health services; assets and economic resources.

Competence e.g. Able to live positively; ability to administer medication; navigate the health system; adopt a patient persona.

2. Competing and collaborating practices

The practice of cascade engagement consists of 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 were in **harmony** or **conflict** with other lifeworld practices, e.g., being a parent; being a spouse; making a living; enacting masculinity.

3. Recruitment or defection

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

- Treatment made easy and accessible; not disruptive to other social practices (minimise impact)
- Bodily experiences; knowing someone who has died from AIDS, or is on ART
- Contact with other 'carriers' or supporters of the cascade engagement practice

Fig. 2 Factors and practices influencing engagement with the treatment cascade

We found cascade engagement to change when factors and practices in Fig. 2 were re-configured. The elements enabling or limiting cascade engagement were not distributed evenly across sites and were conditioned by the social/discursive, cultural, political and economic fabric of a given context.

Conclusions

- Cascade engagement must be positioned within a constellation of practices at the 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, leading to eddies, backflows and stagnancy.
- The often poor fit between the treatment cascade and the lived realities of persons living with HIV call for a broader practice-oriented public health response.

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