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### De-globalizing global public health

*Travelling HIV treatment policies and their imprints on the local healthcare settings in Swaziland*

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## **CHAPTER 7**

### **Discussion and Conclusion**

A ministry of health official is invited by WHO regional office in Nairobi to attend a workshop where Anglophone states receive technical orientation on the new WHO HIV treatment guidelines. Participants are expected to go back to host countries and roll out the new guidelines. The same official attends a workshop in-country by the Ministry of Health collaborating with a donor to orient local partners and service providers on the same guidelines. The main objective for the local workshop is the science and preparations for the scale-up of treatment in order to achieve universal access to treatment. Manuals and standard operating procedures are developed and implementation science tested elsewhere is shared for adoption to aid treatment expansion. Overall the meeting is focusing on getting more people on treatment and bringing treatment closer to PLHIV as a core strategy to scale-up uptake. This is the focus of the facilitator who is the donor and has also funded the workshop; the ministry official is a mannequin lead. Experience and research have shown that, beyond availability and access to biomedical services, there is a horde of other issues that limit uptake of services or universal treatment for all. The facilitator focuses on biomedical factors, however, because he is merely unpacking what is in the guidelines; non-biomedical aspects are not part of the package of guidelines.

Interestingly, there is no discussion of how other components will be catered for, or by whom – drugs for new initiates; the additional staff to meet the ballooning patient volume; keeping staff motivated to provide high quality care; or whether the necessary equipment is available or adequate – none of these are on the agenda. Nor is there any discussion of initiatives to make service friendly, accessible, and practical for PLHIV in the planned scale-up, in order to attract all ART-eligible patients to come to the health facilities as scheduled. Practitioners in the frontline of service delivery share experiences and raise issues, and these are acknowledged as good observations, but nothing tangible comes out of it. All is gone to oblivion, good to know but nothing to do about it.

Reminiscing about this excerpt from my field notes, I cannot help but wonder why this is often the case. Why the disregard of patients' perspective, even health workers' experience, in the conception or development of interventions meant for them? Many explanations race across my mind: Could it be that the silence of the WHO guiding document about non-biomedical issues results in the omission. Or is it deliberate, as the donor wants to push a particular agenda that cares less about non-biomedical issues? Somehow, I cannot shake the

feeling that if non-biomedical issues were of prime concern for the facilitator, they would have featured prominently throughout the agenda of the workshop or there would be a funded technical team to work on them. This is the gangrene that treatment expansion has brought to the public health system: focus and priorities are externally driven, based on externally tested and promoted strategies, and they make the public health system dependent and robbed of agency.

My research complements existing studies, by providing an emic perspective on why PLHIV drop out before ART initiation, and it presents insights from PLHIV on the interventions implemented to expand treatment access. The thesis further interrogates the transnational move of global health science and its interaction with the local (Hardon & Dilger, 2011; Adams & Biehl, 2015). Studying the leaky cascade within the MaxART project, I show how the transnational science of ART and scale-up efforts put pressure on the system, multiplied actors involved in care delivery, resulted in tensions and fragmented services, caused shifts in care practices, and at times negatively affected patients' therapeutic experiences. The research is an expose of the fabrications and distortions produced by the drive for statistical certainty, and explains why so many well-intentioned 'evidence-based' interventions might have contrary impacts (Adams, 2016). This means that implementation science can go wrong and play out differently in different localities.

Moreover, the thesis addresses questions of quality. Health workers, nurses, counsellors, and expert clients are most successful when they are given space to adapt care to the needs of individual patients, something that becomes increasingly difficult in contexts where there are high numbers of patients and pressure to meet targets. This shows that providing good care is highly dependent on what happens at the meso and macro levels, making it critical to understand how HIV care and treatment at the micro level is shaped by the meso and macro

levels. This therefore is the benefit of anthropological approaches, as they aim for a more holistic understanding of HIV treatment access. This includes treatment sustainability, not only in terms of a country's ability to adopt international protocols but also health providers' capacity to take on more work over a longer period of time.

This ethnographic study helps explain why people fail to stay in care despite accessible services, fail to adhere to treatment, and not thrive while in care. Little research has been done on why people fail to access care, especially in contexts where it is readily available in nearby health facilities. My insights in this thesis were only possible because I had direct access to the right data source as an HIV counsellor, providing care as well as studying the arrangement of care within the clinics. I had exceptionally good access to the clinics and to defaulters' files, which would have been highly unlikely if I had not been embedded in the MaxART project. Defaulters are generally hard to find because they are not at the clinic, as the name suggests. Although I had access to files, which helped me start-off tracking down defaulters, I want to underscore the immense effort that was required to find them. When calling did not work either due to a wrong number given, or a defunct number, I had to physically go to the place of abode registered at the clinic. A few times, patients had given false addresses, which could mean the end of the search if no one knew the person of interest. An alternative was to contact the registered next of kin, listed in the patient's file, to find them.

Coming back to the core of the research, the MaxART project was premised on the notion that limited access to health services was a barrier for reaching the desired levels of treatment uptake. It was assumed that if the services were sufficiently close to the people and if the right equipment and expertise were in place, the leaks (patient drop out) in the care cascade would be plugged. Furthermore, a set of deliverables and indicators were agreed upon by the

donors and the MaxART consortium to measure the success of the project: 90% of those in need would be on ART, an increase from 46,883 in March, 2010 to 93,260 by the end of 2014; an increase in the number of people tested each year, from 137,406 in 2009 to 250,000 by the end of 2014; and attrition reduced, from 22% to 10% by the end of 2014 (SAN, 2011). Success of the project was based on quantitative measures, yet patient experiences of the implemented project cannot be measured by arithmetic. This resonates with Adams's (2016, p. 23) observation that sometimes public health programs 'care an awful lot about the numbers', yet metrics do not illuminate the frictions and conflicts created by the implementation of various global health policies. Nor does an arithmetic approach provide insights into perceptions of the quality of HIV care received when the promoted methodologies and strategies are implemented. It is perplexing, how one approach gets priority over others to measure the success of such programmes.

Strathern (2000) shed some light on this issue, asserting that reporting on the drawbacks of a project that is backed by implementation science often remains outside the confines of standard program measures. Harper (2000) also studied this phenomenon and coined the term 'audit rituals' to refer to the process used by development projects to define milestones. He articulated that program indicators are designed to demonstrate programme effectiveness according to metrics that prevent public health programmes from catching the soft issues (see also Schackman 2000; Strathern, 2000). MaxART followed a similar approach. Similarly, Crane's (2013) analysis of Uganda's HIV response found that the expansion of HIV treatment triggered interest from a plethora of donors, prestigious universities, and Western (primarily American) research institutes. He argues that they saw Africa as an investment destination and a goldmine for the production of knowledge, valuable global research that benefits the West. Knowledge production regarding what information matters or qualifies for

public consumption is a highly controlled and protected enterprise whose decision makers are donors and those in American and European laboratories and conference rooms, according to Crane. This illuminated for me the selective nature of highlighting particular aspects of the programme implementation over others, and how it is that those that challenge the hegemonic position of global health strategies and policies receive less attention.

In the case of MaxART, though, native researchers have produced knowledge to feed back to donors. These natives were trained in first-world methods to harvest knowledge on implementation science and produce it for international consumption. Social science findings in the form of ethnographic texts regarding MaxART were constantly fed back to the interested parties, and received with enthusiasm by the funding partners, though the findings remained in the shadows and business continued as usual. The majority of the perceptions and experience-related data about these strategies was perceived as useful by the MaxART consortium and as interesting insights, but they rarely steered a transformation in the way the programme was implemented, let alone a change in the reporting indicators used to measure its effectiveness. Looking at control over knowledge production answers my earlier bewilderment regarding why certain measures are preferred over others, why unintended consequences of the programme remain unreported, and why if they are reported they are not taken seriously. Additionally, the donors' push to meet targets is not only influenced by a genuine desire for universal access to treatment but also by an undercurrent that views Africa as an investment destination and learning site to advance understanding about implementation science, HIV, and ART. But proper auditing of global health programs needs to be a combination of metrics and stories, of data both qualitative and quantitative. Log frames and indicators need to be supplemented and qualified by patient and health worker narratives that provide insight into the embodied experiences of global health policies. Patient narratives and experiences, as Adams (2016, p. 48) puts it, 'create basis for legitimacy and

authority than numbers can solely provide’.

Additionally, bottlenecks in treatment expansion are often conceived as problems that can be resolved only through removing structural and logistical barriers, hence MaxART instituted procedures and strategies to remove structural barriers. As this study has shown, however, even when ART services were readily accessible geographically, and fully resourced, some PLHIV would still not utilize the services as envisaged by project designers. Patient views on care and dynamics outside of the biomedical scope that influence utilization trends of healthcare services are generally insufficiently considered during the design of public health programs. The provision of actual health services was superseded by the quest to demonstrate reliable methodologies tested elsewhere and to generate data. Unfortunately, practical and meaningful evidence derived from patient experiences of these methodologies is often outweighed by the aspirations of donors and technocrats, which that take pre-eminence (Biehl, 2015, p. 129).

I use the metaphor of a leaking bucket to elucidate options for dealing with treatment expansion options. If someone needs a bucketful of water and the one available has a hole, there may be various options to respond to the problem. A first option could be to close the tap, throw away the bucket, and forget that this bucket will ever be useful to collect water. Faced with limited resources to buy a new bucket, a second option would be to attempt to fix the bucket by plugging the holes. A third option could be to keep the tap running, though this would waste much water. In the case of treatment expansion, the first option of discarding the bucket altogether, is similar to halting the provision of treatment or investments; this is untenable. The same goes for the third option of keeping the tap open and hoping the bucket will fill up. Without targeted efforts to resolve the reasons that cause PLHIV to drop out of or not link to care, the investments made to scale-up treatment go to waste and PLHIV will

continue to leak out of the system.

This, unfortunately, is characteristic of the current treatment scale-up landscape in the country. A sensible choice to me would be similar to the second option, which is to fix the bucket. In resource-poor settings like Swaziland where there are few resources and a high dependency on donors, there is no other reasonable option than ART to deal with HIV. The decade-plus of radical prevention efforts to halt HIV in the country did not yield the desired results. But at the same time, providing ART to everyone is not a sustainable endeavour. This means as a country we have to optimize the available option at our disposal: to fix the leaks in the bucket.

There is a caveat for this to be successful, though; treatment expansion needs to grow more steadily than aggressively. It needs to take stock momentarily and put equal efforts and investment into resolving the challenges of limited treatment uptake and low retention rates. Expansion must not be driven by only arithmetic targets, but by PLHIV too. The priority must be quality of care, based on patient-friendly approaches to care delivery, financial resources, and enough motivated clinical staff to serve patients with enthusiasm. Care should not only be physically accessible to PLHIV but also of top-notch quality; poor service should not be the reason for low uptake of services. Implementation science is useful for expansion but it has to be applied with caution knowing that practices work out differently in different settings, which means calling for close involvement of those implementing and experiencing such practices. Otherwise, if such considerations are ignored, proven science may not close the leaks in the cascade as expected.

Whyte (2014) decries the projectification of treatment expansion, which limits the potential of interventions. Projects, or time-bound specific interventions, do not strengthen government system and are hence unsustainable. ART can only fulfil its potential when it is provided as a

cocktail of interventions to PLHIV, in conjunction and partnership with a people-centred approach (Biehl, 2016). To begin with, there is an acute shortage of human resources in resource-poor settings, as is well documented by WHO, yet there is a glaring disregard and lack of support by donors to resolve it. Donors expect data to be collected and reports produced to demonstrate efficacy of implementation science, all of which requires immense human resources, but do not direct investment accordingly.

It would be disingenuous to criticize donors or partners and their implementation approach without mentioning the passivity and inadequacies of the state. Under the pressure of rapid implementation, and with the prospect of receiving large grants, Swazi government officials often agreed to the suggestions of donors and implementing partners but knowing very well that such suggestions would not work. I witnessed junior officers representing the Ministry of Health without the necessary technical competency to engage meaningfully. Strategies to expand treatment uptake were accepted without scrutiny of what it would require of the state. For instance, the state agreed to adopt GIPA without foresight of the institutional requirements for the cadre of expert clients that would need to be absorbed as civil servants. In practice, many donors pulled the strings in the background and the state did not hold them accountable. This research shows that treatment expansion not only incurred undesirable patient outcomes but also strained the public health system. A push for data without the necessary support for human resources and infrastructure, coupled with the constraints of providing quality care in weak and fragile health systems, resulted in undermined quality care and ethics such as confidentiality. As Adams (2016) puts it, this explains why the alleged success of implementation science is criticized as illusionary precision and why it misses ‘other ways of knowing’.

At its conception, MaxART set ambitious targets for scaling up treatment and had good

resources to implement those efforts, but it did not set aside a budget for expanding human resources at the clinics to meet the demand for services. Interestingly, considerable resources are invested to hire technical people within CHAI to push the implementation of MaxART, myself included. Inarguably, technical people were required; the health workers who would actually serve the patients and ensure patients had a positive experience were key but sadly not part of the implementation strategy nor were they budgeted for. Notwithstanding this fact, clinics were expected to implement an array of MaxART activities on top of existing services with the same lean staff complement. Such project interventions for treatment expansion are problematic; they base the attainment of targets and the demonstration of efficacy on existing resources. More problematic is the fact that in making such assumptions, patient experiences and health worker perceptions that should inform real program effectiveness are overshadowed and fall under the radar.

The projectified approach used by implementing donors is not sustainable in its current form. In the case of Swaziland, donors introduced the use of expert clients (as volunteers) through task shifting as a quick and cost-effective strategy to address the health workforce shortage. The involvement of PLHIV in programmatic terms is laudable, as it surely has significantly averted the human resource issues in the HIV response. Task shifting as a strategy is cheap for donors as lay workers are engaged as volunteers (Mdege, Chinove & Ali, 2012), but it is expensive for the state because the state cannot engage them as volunteers as donors do. If the state absorbs expert clients, they have to become fully fledged civil servants, with immense consequences for the state in terms of its budget. Adopting global health-promoted strategies, and providing resources for them, exerts immense pressure on the health system and the state.

Treatment expansion requires a comprehensive approach. Structural improvements are also

needed to accommodate the demand of ART services, such as equipment for monitoring viral loads. My research discovered these aspects (limited human resources and lack of equipment) as a contributing factor for patient attrition in HIV care. These findings question the biomedical claims of ART as a magic bullet for managing HIV infections (Nguyen, 2011). Treatment expansion and successful attainment of MaxART objectives require more than the availability of pills. The provision of ART is only one fix of many, and it only resolves the physiological aspect of infection, not the socio-logistical issues.

### **Closing statement**

Reflecting on this research and trying to make sense of how global patterns link to the state and citizens, I am startled to realize how much the global shapes the local (Crane, 2013). I may not have big theoretical claims to explicate this, but in the course of analysing my data, I couldn't help but notice a thread that was constantly forming. Global tentacles reach deeply into locales. Globally driven policies and strategies not only succeed in their intentions to influence national policies but also affect existing practices and norms at the lowest levels, shaping the personal experiences of those who apply and experience the strategies in use. Before my involvement in this research, I viewed the state as a powerful, independent entity with autonomy to do whatever it deemed to be a priority for itself and citizens. However, this research shows that it is not so. The state is controlled by a very powerful yet invisible arm that has its base in the global. As the years go by and HIV increasingly becomes of less interest for global superpowers, health care is becoming yet another conduit to emasculate state sovereignty. Global donors push for reform through offering funded programs, and the Ministry of Health doesn't push back, which has allowed them to steer national priorities towards donor interests.

Personally, I am sceptical of all such programs like MaxART, a pilot program wanting to

prove its efficacy and become a learning site for other countries. I worry about the long-term sustainability of such projects. What will happen when the MaxART budget and timeline has come to an end, and the state does not have funds to continue to service all the people already put on ART? Even in the current state of affairs, partners direct support towards technical assistance and provision of equipment for treatment expansion while the state is expected to do the rest, including putting systems in place and providing structure and personnel to make treatment expansion possible. Although the implementation science demonstrates a level of success, one might ask how the state will provide the resources needed to inherit these projects when funding runs dry. Will such a project be sustainable? What will happen if global health priorities about HIV change and funding dries up? What will happen to the huge investments already made for treatment expansion to ensue (Prince, 2012), including the clinics built, equipment procured, and training priorities steered towards HIV programmes?

These fears are authenticated by the trail left by the prevention era of the HIV response. Once-busy male circumcision clinics are now under-utilized, with sophisticated equipment marginally used and operations now scanty. Buildings that were once used as Voluntary Counselling and Testing centres are lying idle or occupied by other business with only signage remaining to show their previous function. Hotels, workplaces, and public toilets throughout the country have empty condom dispensers that once were filled with free condoms, but funding to fill these receptacles has dried up. All remain as an eyesore and reminder of the forgotten hype of HIV prevention. It is unpleasant to raise these provocative observations now, as all minds are set on expanding HIV treatment to halt new infections. To apply lessons learned from the prevention era, there is a need for foresight to mitigate undesirable consequences of the treatment maze.

It is my sincere hope that this thesis triggers a greater realization of the need for further research into what else implementation science does, beyond just expanding treatment. Strategies need to be evaluated beyond the binary perspectives of whether they are effective or what challenges arise. It is befitting for research to focus on what failures are concealed by the success stories of appraised global health strategies. What are the resonances and dissonances of these acclaimed strategies? Researchers must ask how global policies for treatment expansion may invade a society, how they can hamper, alter, or configure new practices, shape norms and meanings, and affect social processes. In the quest for patient involvement and with manifold clinical trials and research done to improve services, what forms of engagement are used to involve patients? What should constitute a gold standard of participation in patient care? As donors call for state, civil society, and patient engagement in shaping policy, we must ask: what forms are now being used, what proof validates that participation has occurred, and what meaningful outcomes have resulted? Lastly, as volunteerism is a backbone for treatment expansion in the face of a health personnel shortage, there is need to critically question what is at stake when crucial programmes such as this one rely on a cadre of volunteers.