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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 1**

### **The Genesis of the PHD Trajectory and Studying the Leaky cascade**

## **Introduction**

In early 2011, I resigned from my then job at UNICEF as a child protection officer and joined the Clinton Health Access Initiative (CHAI) as an access-to-medicine analyst. Working at a high level in international development had not excited me; I could not see the effects of the work I was doing and it all seemed like a mirage. I had a strong desire to work in health development, where it seemed results were easier to see, for example if you give a painkiller to a patient the pain goes away. Out of curiosity I joined a meeting in my new workplace. CHAI had received 9 million euros from the Dutch Postcode Lottery to implement a 'dream' pilot project, MaxART, 'to maximize antiretroviral treatment (ART) to prevent new HIV infections' (Stop AIDS Now, 2011). The meeting I attended was a brainstorming session that brought together all of the partners to develop strategies to implement the proposal. Each partner shared how he or she intended to fulfil their mandate in the project.

One of the partners in the project was the Graduate School of Social Sciences, University of Amsterdam, whose role was to conduct social science research and inform interventions in the project. Professor Ria Reis shared the intentions of the university to build capacity among local researchers instead of bringing in external expertise. Two people from Swaziland with a minimum qualification of a master's degree would be recruited and sent to Amsterdam for training in social science research for health. Professor Reis said there would also be a possibility for the researchers to get funding at the end of the three-year project to write a PhD thesis. The researchers would attend courses for three months in Amsterdam, return to Swaziland to do a situational analysis, and return to Amsterdam for another five months to finish the coursework. I must say that my ears perked up when I heard that. The idea of short periods away from home was appealing, as I did not want to do further studies that would take me away from my family. It was the chance I was looking for to work in health development.

During a break, I found Professor Reis at the coffee station. I used that opportunity to get further details, and the more information she divulged, the more I became interested. To cut a long story short, I was selected for one of the positions as a social science researcher in the project. Each researcher had to focus on an area of our choice within the wider spectrum of the continuum of HIV care to understand the factors, dynamics, and circumstances for low uptake of HIV services. Looking back, I realize that it was during the conversation I had with Professor Reis during coffee break that my PhD journey really began. Unlike other PhD projects in anthropology where researchers usually have a great deal of leeway in developing their research project, I was from the start embedded in the MaxART project. Additionally, I knew I would only receive funding to write up my research as a PhD if I proved myself as a skilled researcher over the next three years.

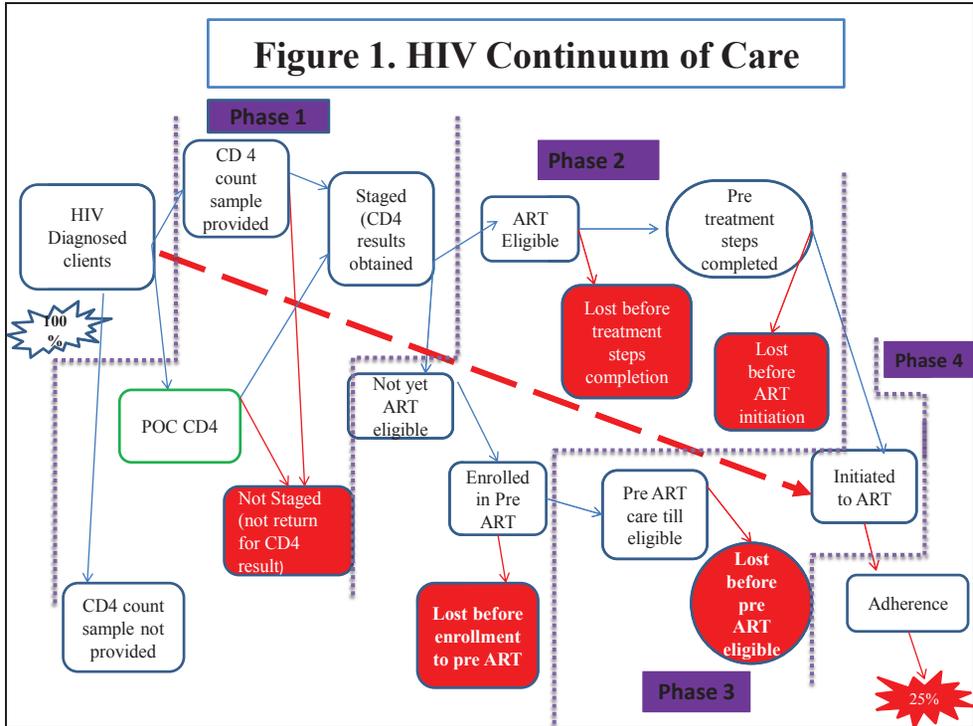
### **MaxART, ‘the leaky cascade’, and the PhD trajectory**

MaxART was conceived with the aim to encourage the research community, activist organizations, and global health implementers to collaborate with the Swazi Ministry of Health to identify structural barriers treatment uptake, increase HIV testing rates, gain in-depth insight on lived-experiences of PLHIV and safeguard that the aggressive approach to HIV treatment expansion does not undermine human rights. The targets for the programme were: to identify and enrol 90% of those in need into HIV treatment programs (this number increased from 46,883 in March 2010 to 93,260 by the end of 2014 due to new WHO guidelines on treatment thresholds that indicated people living with HIV should start treatment earlier). The number of people tested each year had to increase from 137,406 in 2009 to 250,000 by the end of 2014. Lastly, the loss-to-follow-up rates of those in treatment reduced from 22% to 10% by the end of 2014 (CHAI and Stop AIDS Now, 2011: np).

The proposed ART programme focused on testing more individuals, initiating people early

on into treatment, and attaining high retention rates. After I conducted a situational analysis of the ART programme in Swaziland in 2011, and carefully analysing the WHO-adopted comprehensive guidelines for care for all PLHIV, one issue stood out for me as a stark omission from the MaxART programme. The guidelines explicitly stated that all people diagnosed with HIV, even those ineligible for ART initiation during diagnosis, are to be expediently linked to HIV care. At the time of the study, none of the MaxART-proposed interventions focused on optimal linkage to care and retention to pre-ART, as stipulated in WHO guidelines. Yet for early ART initiation to be achieved, expedient linkage to care and retention of the pre-ART cohort of PLHIV would be necessary.

In February 2012, I attended a Treatment as Prevention (TasP) workshop in Amsterdam, where a researcher from the United States (Ingrid Bassett, representing the Harvard research team) shared findings of research conducted in South Africa that focused on patients who dropped out of what is usually referred to as the HIV continuum of care, the same cohort of patients I was interested in studying (Bassett et al., 2010). Her presentation focused on attrition rates among patients at different phases in the continuum, known as a ‘leaky cascade’ in public health terms. Digging into the literature, I learned that other researchers had studied the leaky cascade to understand barriers to care and reason for patients leaking out of care (Kranzer et al., 2010). However, none of the studies investigated *why* patients eligible for ART dropped out of care or *why* eligible patients were not linking to care. The existing research only highlighted attrition levels and the phases where attrition occurred. Those that attempted to suggest solutions hinted at logistical fixes – the need to secure medicine delivery, improve recordkeeping and health worker expertise, and the need to shift tasks among health care workers to make it easier for more people to access treatment quickly. None of the studies addressed individual or social reasons for attrition from the perspective of either patients or frontline health care providers.



Note: Adapted from Rosen et al., 2007: p.2

The term ‘leaky cascade’ caught my attention because it seemed to be symbolically portraying patients as leaking out (not easily noticeable), instead of suggesting that they might be choosing to drop out of care, sometimes with good reason. It connoted a problem on par with a plumbing mishap, requiring a quick fix to stop the leak. This framing of a health systems issues as akin to a plumbing problem provided the focus for my research on patients who dropped out of HIV-related care. I decided to explore if a ‘system fix’, in line with the approach and focus of MaxART, was indeed all that was needed to stop patients from ‘leaking out’ of the health system pipeline. But, in the back of my mind, I wondered if decentralizing services, making necessary equipment available, and providing expertise to operate the equipment – the fixes that were on the table – would be sufficient to resolve the social, economic, and psychological reasons patients fell out of care.

aims included an effort to contribute knowledge about the dynamics and circumstances behind the failure to link to care those eligible for ART, as well as to map the reasons that uptake of ART was delayed. Because there was limited knowledge on these subjects in Swaziland (and elsewhere in Africa) at the time, the MaxART programme approved of this focus for my research. Following my preliminary research, I began to question why the national ART programme seemed heavily skewed towards putting individuals on treatment, and not focused on individuals who were HIV positive but not yet eligible for ART. This seemed an important discrepancy to me, given that the guidelines for comprehensive HIV care emphasized enrolment in a medical care programme as an important entry point for the continuum of care. One way of interpreting this would be that the national response guidelines emphasized enrolling people living with HIV (PLHIV) into care over helping PLHIV to stay healthy *without* ART.

At the time I began my study, there were many instruments being used to ensure maximum adherence among ART clients, namely treatment guidelines, counselling manuals for seemingly non-adherent patients, and the tracking of so-called treatment defaulters, i.e., people who stop treatment after being enrolled in a programme. Conversely, there was much less effort and support for pre-ART clients and no tracking mechanisms in place to monitor prophylaxis utilization. From my perspective, this was problematic because research had shown that one of the major barriers to reaching people with HIV care services was their fear to test (De Witt and Adam, 2008; Meiberg et al., 2008). It seemed logical to me that, once people overcame that fear and got tested, a supportive health system would do its best to provide services to everyone that tested HIV positive, regardless of their eligibility for ART. Yet, in Swaziland, many PLHIV dropped out of care after testing positive. Too often, people collected their results and disappeared from clinic, making it impossible for health care workers to offer support to manage the newly diagnosed infection. The presumption built into

the MaxART programme was that dropping out of care was mainly a logistical problem to be solved by bringing services closer to people and making services free. While I could see the logic of that reasoning – as research has shown that barriers to care and adherence can often be linked to rates of access (Hardon et al., 2007) – thinking as a critical social scientist, I also wondered about the individual and social circumstances and dynamics that might prevent people from linking to care.

The social science training offered by the University of Amsterdam required that I follow some courses in the Amsterdam Master's in Medical Anthropology, a programme that emphasized the use of ethnographic methods to understand health problems. This methodological approach encourages researchers to become immersed in the daily lives and life-worlds of the people being studied in order to understand better the social complexities of health and disease. Personally, this motivated me to strive to have first-hand experience of the issues I was investigating. To start-off the research, I trained as an HIV counsellor, which allowed me to participate at the frontline of HIV service provision, where I had to endure work conditions similar to health workers. I learned how it felt to work under the pressure of programmatic targets, as well as the difficulty of balancing the push to reach targets with the desire to provide ethical and high-quality patient-friendly services. I was also able to observe how ART was administered in everyday practice and how protracted the process was in the two clinics where I attached as a counsellor trainee.

Further, because the clinics where I conducted research were sites for MaxART and other international interventions, I was able to observe a context in which global HIV treatment policies, guidelines, and principles (implementation science) were being actively implemented. Implementation science is the study of the systematic application of research findings and evidence-based practices to improve the quality and effectiveness of health

services (Eccles and Mittman, 2006; Madon et al., 2008), and this approach heavily shaped the MaxART project. The proven science included adoption of strategies such as task shifting, nurse-led ART initiation (NARTIS), provided-initiated HIV testing, point-of-care testing, and the involvement of PLHIV in care that had proved to be effective to improve uptake of ART treatment elsewhere. I spent many days with health workers and I saw the amount of work and effort they put into delivering health care services. I witnessed many moments of despair – as expected from health workers who had few resources – and moments of exhilaration, for example, when a life at the brink of death was saved. I sat in on counselling sessions, interviewed patients, and via informal discussions listened to numerous patient stories about the frustrations they experienced in getting timely access to quality care within a highly burdened health care system. I also became privy to intimate details of what it means to be a health worker, including the psychological pressures and stresses they endure; what it means to have one's HIV infection status used as a qualification for employment; and how the desperation to sustain a livelihood put PLHIV peer mentors ('expert clients') at risk of labour exploitation. I saw cracks emerge and grow in a health care system that was put under extreme pressure from global actors that were concerned about using metrics to measure results and effectiveness of strategies. In short, I observed the imprints left by global HIV treatment policies on the local public health system, health workers, and patients.

#### Development and anthropology meet

In my 10-year professional tenure as a development specialist, my orientation to understand utilization patterns of development services was mostly skewed towards interrogating structural factors. I had not explored the perspective of the end-user. My professional experience working for funding agencies and supporting national entities to implement

externally driven policies certainly influenced my perspective. Most, if not all, health and development policies in Swaziland (certainly all those related to HIV care) emanate from the global level (bilateral donors, international NGOs); the Swazi health care system is generally expected to adopt and implement policies, putting into practice mandates developed with little understanding of on-the-ground realities. To ensure successes that can be measured in accordance with global standards, funding agencies routinely monitor whether the state adheres to international guidelines, conventions, and policies. The stakes are high: failure to adhere, or simply failure to produce appropriate data regarding adherence to global norms, can result in the withdrawal of substantial funding.

I worked for the UN and CHAI and saw with my own eyes how these dynamics play out. UNICEF established its presence in the country to promote children's rights and enforce the state's commitment to protect children from harm. My role was to support the implementation of projects to improve the country's status and standing in international ranking as stipulated by UN and other global bodies. In my job at the United Nations World Food Programme (WFP), my responsibility was to monitor donor-funded food aid and ensure it was received by eligible households. When there was a drought, the state was required to declare the situation a disaster before donor agencies could support the country. In essence, declaring disaster is a confession of the state's failure to respond to the needs of its own people. I felt like a mere tool of the donors, monitoring my country on behalf of various global entities and affirming that my state was incapable. Hence, my perspective was limited to a top-down approach, only interacting with the state and citizens as mere passive recipients. Such control and strict monitoring of the state by global entities rendered the state incapable of autonomously performing its role, thus making external support the esteemed messiah necessary to rescue the state.

Although the UN described its approaches as people-centred, participatory, and inclusive of all concerned, the interactions I observed were always top down. Michael Edwards' *The Irrelevance of Development* (1989), which I read during my tenure in development work, definitely influenced the focus of my doctoral research. Edwards questioned the development approach used by donor agencies, of bringing in outside experts to craft solutions for local communities ('expertizing solutions'), made me begin to question the development apparatus that employed me. Similarly, Ferguson's (1994) account of development efforts in Lesotho prompted me to question for whom development is really meant. As an employee in the UN system I knew for a fact I implemented projects that had very little success in transforming communities. If such projects had been successful, then one would expect poverty to be eliminated, or at least significantly reduced, especially given the amount of development efforts and resources invested to end it over the previous decades. One might say that my ambivalent experience working in the world of international development primed me for my encounter with anthropology and ethnographic methods, helping me to shift my analytical focus from the macro to the micro level, and motivating me to focus this thesis on examining the extent and degree to which the global HIV agenda simultaneously shaped the state and its citizens.

Over time I have come to realize that my development orientation was myopic. It could not explain the multi layered sociocultural, economic, and political dynamics and intricacies, and how these affected the utilization of services and behaviours towards programmes. Also, the development approach did not interrogate how the policies and strategies adopted to achieve development goals influence or alter existing practices and norms, for the better or worse of their intended beneficiaries. My development experience and training conditioned me to view issues from the lens of external stakeholders, and to interrogate peripheral and superficial issues such as physical barriers, stakeholder involvement, and

stakeholder accountability. I realized that the state was a constantly moving entity in the implementation of development programmes; global partners expect the state to fulfil its commitments, as do citizens. Unfortunately, due to power dynamics, the state must satisfy the expectations of global health entities before those of its citizens.

My training in anthropology illuminated the value of investigating people within a web of sociocultural constructs and how cultural beliefs could affect the way people assign meanings to their life experiences (Green, Richard & Potvin, 1996). During an illness episode in a family, the understanding of the aetiology of the illness and consensus in the kinship network determines the therapeutic pathway that will be pursued (Kleinman, 1980). Patients' feelings, beliefs, and knowledge about an illness are equal in importance to the expertise of the medical practitioner in achieving desired health outcomes. This makes management of illness a partnership between the practitioner and the patient. In particular, Kleinman's arguments regarding the importance of attending to the sociocultural contexts of patients and healers profoundly influenced my approach to understand health-seeking behaviours and patient perspectives, and why patients' explanatory models matter in their quests for healthy lives. This was a fascinating discovery for me because it challenged the orthodox, positivist, and hegemonic approach held by biomedical people (Barry, 2006) that presumes that medical practitioners are the only experts and patients are passive agents. Medical anthropology offers key and complementary framings for understanding the pathways for disease management, not least of which is that patients are a mandatory partner in disease management.

My approach to understanding the leaky cascade was heavily influenced by my anthropological learning, leading me to include both patient and frontline health workers' narratives about why patients dropped out of care rather than attributing 'leakage' to

logistical problems only. I positioned myself within the sociocultural strand of medical anthropology to explore the barriers that caused individuals not to use accessible HIV services or drop out of care and to explore how cultural constructs influenced individual decisions regarding which therapy to pursue or whether to stay in care. Wanting to achieve a more holistic perspective, I set out to examine both the logistical constraints and a range of other factors that resulted in the non-uptake of services. To understand how players and practices influenced patients' utilization or non-utilization of readily available services, I studied three levels: the macro level, which includes global health proponents and their promoted policies; the meso level, which is the public health system; and the micro level, made up of patients and the larger community. I examined the three levels in connection to local social, political, and economic dynamics to determine how each level interacted with the other and influenced or affected the uptake of ART within the continuum of care. Multi-level investigation looks at how group-level variables are related to individual-level outcomes and explains how macro-level processes have an impact on individuals at the micro level (Diez, 2002, p. 588). The multi-level perspective enables us to illuminate the underlying processes at various levels and analyse how they are linked to each other, in order to understand what takes place at each specific level (Van der Geest, 1990). In the context of this study, multi-level analysis provides an approach to explore what happens when a wave of global health policies adopted to scale-up ART uptake meets the local context, and to analyse how the two affect the constellation and administration of care, reconfigure and reify the meanings of care, and shape experiences of PLHIV in local health settings. It is about understanding the leaky cascade from an emic perspective: how is leakiness resolved through policies and strategies, and how do these strategies work out in practice?

## MaxART and anthropological insights

Around 2010, the HIV medical response took a new turn; growing evidence showed that in order to realize the full health benefits of ART, people needed to start treatment earlier than had previously been thought. To achieve this, it would be necessary to promote routine and earlier testing for HIV, earlier initiation for those eligible for ART, and optimal adherence rates of 95% or above. In essence, this meant many people would start treatment before experiencing any symptoms of HIV and that they would be take antiretroviral medications throughout their whole lifetime (Granich, 2009; Cohen et al., 2011). In 2011, the shift that was already in process got new impetus when the findings of the HPTN052 study were published. The HPTN052 study's ground-breaking evidence showed that early ART initiation not only reduced transmission but had the potential to prevent new infections (Cohen et al., 2011; Powers et al., 2011). The trial demonstrated that lowering viral loads among infected people through the use ART greatly reduced the risk of them infecting other people. The authors argued that theoretically it would be possible to halt the spread of HIV if enough people were put on treatment. Although this was not the cure people had been long hoping for, the evidence was used to motivate radical qualitative shifts in global HIV treatment policies and practices, as well as to motivate international donors to invest in a rapid scaling up of HIV testing and treatment activities in countries like Swaziland that were hard hit by HIV. ART quickly became the biomedical 'magic bullet' that promised to halt new HIV infections (Nguyen, 2010).

The global shifts in treatment policy were multiple. In most cases they were developed in relation to the evidence of what worked in terms of a biomedical response, failing to take into account the realities of implementing new policies and guidelines on the ground. For example, when ART first became available in Swaziland and other resource-poor settings

around 2003, people were started on treatment when their CD4 levels fell below 200. In 2010, the threshold increased to 350, making many more people eligible for treatment. This meant more patients had to be attended to in the public health care system, regardless of whether or not greater resources – human and material – were made available. In most cases, clinics had to absorb the extra patients without any additional financial support. In 2013, the threshold shifted again, this time to 500. Despite being heavily burdened already, both the state and individual health care facilities were pressured to expand treatment access rapidly. This precipitated rigorous and radical efforts to enrol as many people on ART as possible. However, the response faced formidable challenges such as acute human resource shortages (Van Damme, Kober, & Laga, 2006) and the treatment gap widened as more people became eligible for ART. In an attempt to offset the heavy burden of scale-up, the WHO launched its Treatment 2.0 framework (2010–2015), which outlined ‘task shifting’, as a solution. Task shifting, or the shifting of medical tasks from higher to lower cadres of workers, it was argued, would stimulate innovation and improve efficiency in resource-limited countries where there was a shortage of workers. The WHO asserted that states should adopt the framework to achieve the milestones for treatment that were being promoted on the global level.

By 2010, Swaziland had addressed many challenges to universal access but some barriers persisted and impeded efforts to further increase access to HIV treatment. They included limited access to treatment (because of cost and distance), limited infrastructure, lack of capacity in treatment clinics, and preference for traditional medicine to manage HIV-related sicknesses. The MaxART programme was conceived in Swaziland at this juncture, to get rid of structural factors that limited access to treatment. It was conceived as a trial project to pilot implementation of the findings of the HPTN052 study. The aim was to eliminate virtually all new HIV infections within Swaziland, a country with a generalized epidemic

profile. In addition to this already-ambitious aim, the trial also had to provide proof to support the concept of using treatment as prevention, meaning it was required to document a clear relation between the intervention and declining HIV incidence. The objectives of the project were multiple: to ensure universal access to treatment by addressing barriers faced by individuals in need of HIV treatment; to better understand the realities of people living with HIV; and to monitor the extent to which the ambitious expansion of HIV treatment was being carried out within a human rights framework. The project had three key areas of focus: achieving universal access to testing and treatment for those eligible; assessing the impact of universal access to testing and treatment on prevention efforts; and demonstrating the results of treatment as a form of prevention in high-prevalence settings. MaxART interventions focused on community mobilization to create demand for HIV testing, bringing ART services closer to hard-to-reach places, and instituting follow-up mechanisms to ensure patients remain in care and treatment (Stop AIDS Now, 2011). To achieve this, various globally derived policies, principles, and strategies were implemented or intensified.

### **Key biomedical concepts for treatment expansion**

In this section, I introduce some of the key categories and concepts of this study. Because my research took place in a highly medicalized field, I was inundated with medical terminology. My aim here is to offer basic definitions for the reader as well as provide some anthropological context concerning the ways that these categories and concepts were operationalized in practice.

#### **‘Lost to follow up’ and ‘defaulters’**

The phenomenon of patients dropping out at different points of the HIV continuum of care, from HIV diagnosis to ART initiation, is referred as a ‘leaky cascade’, and clients that drop out at any point are referred as ‘lost to follow up’ (LTFU) or ‘defaulters’. I observed that the

term 'LTFU' was indiscriminately used for all clients who dropped out of care, regardless of the reason. No matter whether a patient missed an appointment because they did not have bus fare to go to the clinic, changed to a preferred clinic, was untraceable via phone or physical address, was deceased, had refused treatment intentionally, or was inhibited from using antiretroviral medication by a significant other, all were all put into this one category.

Such an amalgamation of cases is problematic because it represents a false picture of clients who did not return to care as scheduled. First, it conceals real issues for patients that drop out, especially those related to the inefficiencies of the health system; this inhibits the system from recognizing, diagnosing, or resolving internal problems. Instead, it shifts both attention and blame to the patient. I observed that clinics were often constrained by limited resources to track patients, and when patients couldn't be traced physically, such clients were categorized as LTFU, but this didn't always mean they were out of care. As I traced and followed up with LTFU clients, I found a number who were enrolled in another clinic and who were perfectly adherent. The lack of a mechanism to trace clients when they changed health centres (such as an automated medical record system or use of unique patient identifiers) resulted in clients being erroneously labelled. Furthermore, I found that patients rarely dropped out of care consciously, and most often just missed appointments. The qualifying criterion for a person to be categorized as LTFU or defaulter was time: failing to return to care for 7, 14, or 90 days. This categorization does not recognize that some clients will need more than 90 days before returning to the clinic for ART initiation to commence.

In almost all cases, with the exception of patients who had died, patients referred as LTFU were actively navigating barriers encountered in their lives and planned to return to care once these were resolved. Branding patients as defaulters portrays an inaccurate picture of PLHIV as unwilling and uncooperative to take treatment and conceals their efforts to return

to care. Importantly, this prevents health workers and policy makers from imagining the many PLHIV who will not adhere to timeframes for enrolling in care and initiating ART due to a wide range of issues, from individual psychological to social and structural. Failure to recognize these limitations also makes it impossible to imagine solutions. I argue that HIV programme implementers need to review the criteria of what constitutes defaulting or LTFU and that they should only classify people as LTFU after exhausting all options for physically tracing and instituting electronic tracing to monitor clients' movement from one facility to another. My hypothesis is that such an approach would not only dramatically lower the number of patients categorized with the stigmatizing label, it would also improve our understanding of the complex mechanisms that combine to delay people's efforts to access treatment. Once a patient is categorized as a defaulter, the term carries pessimistic undertones; when defaulters return to care they often encounter unpleasant reactions from health workers. Furthermore, once a PLHIV is labelled a defaulter the health centre stops looking for them, which mean the patients lose out on opportunities for support.

### 'Adherence'

Adherence to treatment was considered a key indicator of success when measuring the effects of treatment scale-up. In order to measure adherence to treatment, MaxART adopted the pill count method as stipulated in the WHO treatment guidelines. The number of pills dispensed for a period of time was compared to those consumed by the time of the next appointment. Patients needed to score above 95% to be deemed adherent. This was an aggressive approach to patient monitoring that aimed to promote responsible patient-citizens. The tacit agreement at work seemed to be that if the state provided medicines, the citizens had a duty to take them as prescribed so they could improve their health and remain productive (Mattes, 2011). Though patients were strictly monitored for adherence, long-time

patients were aware of how the adherence formula was calculated. Because there was an incentive for scoring 95% or above for three consecutive months (such patients were given two months' worth of medication instead of one, meaning fewer trips to the clinic), they undermined the process, strategically bringing the number of pills that would tally as needed to guarantee them a high score for adherence. In practice, this meant that non-adherent patients could be categorized as adherent. Just as we must question public health categories that pigeonhole people who try (and sometimes fail) to navigate complex social circumstances in order to access treatment as 'LTFU', so too should we question punishing monitoring mechanisms that encourage experienced patients to find ways to game the system.

#### 'CD4 count'

A CD4 count is a lab test that measures the number of CD4 cells in a blood sample. It is an important indicator of how well the immune system functions. In HIV treatment, it is a threshold used to determine initiation onto ART. The CD4 count is used to determine the body's ability to fight opportunistic infections as a result of HIV infection. The phrase 'pre-ART' refers to individuals who are HIV positive but not yet eligible for ART initiation according to the WHO guidelines. At the time of the study in 2011, those with a CD4 count of 350 and above were classified as pre-ART. Individuals with a CD4 count lower than 350 and already initiated on ART were considered to be in the ART phase. The MaxART project used similar guidelines to scale-up ART treatment. However, in practice most PLHIV used CD4 counts as a marker of health, and would use their knowledge of their CD4 count to inform decisions about when to initiate treatment. According to many, a CD4 count below 350 did not necessarily warrant initiating ART, especially if there were no other indicators of disease. Some HIV patients in the study, for example, only started treatment when they

developed other symptoms; often rapid weight loss motivated people to seek out a treatment programme. From a biomedical perspective CD4 results provide a clear indicator of when to start treatment; from a patient perspective, CD4 results sometimes hampered early treatment initiation.

#### ‘Task shifting’

Task shifting includes a range of strategies to counter human resource shortages for expanding HIV treatment. It involves retaining existing cadres of workers to prevent brain drain and train new cadres of human resource. For the latter, less specialized tasks are delegated by nurses to trained PLHIV known as ‘expert patients’, and these PLHIV provide a wide range of non-technical HIV services. In the Swazi context, doctors delegated some tasks to nurses, and nurses then shifted tasks to lay health workers in what is termed ‘NARTIS’ (nurse-led ART initiation service). When task shifting was first envisaged, it was assumed that it would expand treatment access, provide patient-friendly services, and relieve some of the burden on the health system (WHO, 2007). It did achieve some objectives, like facilitating the expansion of the number of people in treatment and diverting human resources needed for enrolling individuals to care. However, findings in this research suggest that task shifting compromised the quality of service delivered to clients; it protracted the provision of care in the two clinics where research was conducted. Before task shifting was adopted in Swaziland, a patient was counselled and tested by one health worker (a nurse) and then enrolled into care. This meant the patient queued at one service point and then interacted with one health worker; with task shifting the tasks were divided into four processes: pre-test counselling (counsellor), testing (phlebotomist), disclosure of results (counsellor), and staging and prophylaxis (nurse). These four actions are done by four different workers, which means patients must line up in four distinct queues.

As the tasks are assigned to lower cadres, the impact does not end at shifting tasks but also affects the way care is arranged and provided. As clients move from one health worker to another, they could derive different therapeutic experiences. This demonstrates that, though task shifting had a huge advantage to close the patient-to-health worker ratio, it led to shifting care practices too, which was an unintended and undesirable consequence. This tells us that while there are good intentions behind adopting global HIV health policies, to ensure treatment reaches all people that need it, there still is need for caution in doing so. Implementation science cannot be replicated bluntly; there is need to contextualize it as the impact can play out differently in different settings due to distinct dynamics that differ from where the effects are manifested. Also, through task shifting health workers were added to health facilities and PLHIV received embodied services from expert clients, but the proponents of the global health policies did not invest in structural improvements to the clinics to accommodate the swelling number of patients. As a result counsellors did not have proper space to deliver confidential counselling services and patients were usually crammed in small rooms, which made air circulation difficult and increased chances of re-infection for airborne diseases such as tuberculosis. Furthermore, the welfare and positioning of expert clients to assume nurses' duties in the health system was not prioritized. They remain volunteers to date, eleven years since HIV treatment started in Swaziland. If task shifting is to work, donors need to also support long-term structural investments in the public health system.

#### Greater Involvement of People with AIDS (GIPA)

GIPA is a framework that was adopted to promote the participation of PLHIV in shaping and influencing policy, both globally and at local levels, and to ensure they would not be just passive recipients of HIV treatment. The WHO recommended it as one of the pillars for

treatment scale-up to create a quality, relevant AIDS response (Van Roey, 1999). PLHIV were supposed to inspire and motivate other PLHIV and to facilitate trainings and sensitization forums. However, with time, the scope of PLHIV involvement expanded to their full-time engagement in the provision of treatment, as was the case with expert clients in Swaziland. Expert clients were initially engaged to assume counselling tasks but gradually they performed more duties in the clinics such as conducting rapid HIV testing, disclosing results, explaining technical information to patients such as CD4 count, taking biometric data, and enrolling patients to care. Because their engagement was under the guise of GIPA, PLHIV provided services for free, as volunteers; these same services had been previously rendered by paid nurses, prior to task shifting.

I find this development problematic. In resource-poor settings like Swaziland where there is a shortage of health workers, a cadre that has acquired experience to close the human resource gap is a valuable resource that needs to be grafted onto the public health system and institutionalized. Despite being what would seem like a pragmatic solution to a health worker shortage, expert clients have not been formally absorbed into Swaziland's public health care system. In failing to do so, I believe the state undervalues both the skills of expert clients and the key role that they perform in ensuring the success of treatment expansion. Lacking biomedical qualifications, expert clients are often seen as being in an inferior position in comparison to medically trained staff, such as nurse assistants, even though they perform similar duties. I see this is an abuse of GIPA: this global instrument is used to justify the employment PLHIV for the benefit of the ART programme, but because they only receive a stipend and no proper structures to protect them or long-term investment in the public health system, expert clients are essentially exploited. GIPA calls for voluntary and partial involvement of PLHIV, not the large scale and scope of work being performed by expert clients in Swaziland and across Africa. The work conditions for expert clients that

have emerged in Swaziland are also an indication of weak activism in the country. If the national PLHIV organization was stronger, as documented in South Africa or Brazil (Robins, 2006; Biehl, 2004), it undoubtedly would advocate against such abuses and call for change. I believe my research suggests a need for a review of the GIPA principle and how it is being used to elicit labour from PLHIV. We need to redefine GIPA so that donors do not use the GIPA framework to engage expert clients, but instead engage PLHIV in paid service delivery based on competence and skills they possess rather than HIV status. This will prevent PLHIV from being exploited as a source of cheap labour by funding implementers that do not allocate a budget to hire expert clients but instead engage them as volunteers.

#### Why focus on the leaky cascade?

The primary problem that captured my attention was the fact that at the inception of my study there was treatment gap of 36%, meaning that 36% of people eligible for treatment were not enrolled in an ART program. Most specifically, I wanted to investigate practitioner-client interactions within health facilities in order to assess if patient experiences contributed to non-uptake of HIV treatment services. Also, I wanted to investigate how gender and power dynamics within the family, the community, and the health facility shaped decisions to stop care as well as shaping notions of health care. Furthermore, anthropology introduced me to the role of rumours and perceptions that can significantly shape health seeking behaviour, hence I wanted to investigate the prevailing societal constructs and meanings about HIV treatment, and how these influenced decisions to stay in or drop out of care, and constrained access to or uptake of HIV services.

MaxART relied heavily on ‘implementation science’, adopting global strategies and principles to scale up HIV treatment. In my research, I interrogated the effectiveness of this so-called science from the perspectives of both health provider and patients. My goal was to

assess if interventions had an effect beyond helping to expand treatment, and whether there might also be side effects that potentially cause patients to leak out of HIV care. I investigated a range of global processes and policies that came with treatment scale-up to understand how they affected care arrangements in local clinical settings and shaped patients' experiences.

## **Theoretical arguments**

### Travelling policies

The thesis tells a story of how a health system and health workers deal with an avalanche of externally derived policies to combat HIV infection, and how patients deal with a life-threatening infection that has the potential to affect the fibre of their being as well as their relationships. Furthermore, it elucidates the imprints left by the policies as they travel to each destination. Policies guiding the HIV response, originating in Geneva and New York (where the WHO and Global Fund are headquartered, respectively), journey all the way to Swaziland. The concept of travelling policies was borrowed from Hardon and Dilger's (2011, p. 136) analysis, in which they sketch the journey of global AIDS medicines and how they shaped norms and transformed individuals, families, and communities responding to AIDS and its treatment regime. 'Travelling' is used as a metaphor to underscore that these policies are externally derived and locally adapted. In the context of this thesis, travelling policies refer to HIV treatment strategies, guidelines, and protocols on who, how, and when to treat, which emanate from global circuits yet are implemented in local health care settings. The central aim of the thesis is to unravel how the global policies play out when implemented at the local level, and what imprints they leave beyond the arena in which they are intended to perform.

Ferguson (1994, p. 180), when studying development patterns in Lesotho says ‘instead of asking, can aid programmes help their intended recipients (the poor), be effective and benefit them, we should ask what is it that aid does beyond helping the people’. Ferguson calls for further enquiry into what else, besides reaching their intended targets, aid programmes do. In this case, it means studying what global HIV policies and strategies do besides increasing treatment rates, and investigating the trail they leave as they trot the globe. This implies that aid or external support has far-reaching tentacles.

The thesis does not address the effectiveness of HIV policies, protocols, and guidelines; rather it is an expose of what else happens as the policies are implemented. I show how global commitments put immense pressure on governments to allocate specific budgets towards healthcare, as a result of the Abuja Declaration. Furthermore, governments are expected to take over projects from implementing partners after some time, which thus affects Ministry of Health priorities. The scope of work for health workers has expanded tremendously as various interventions are added without due consideration for compensation or motivation. Their remuneration is not reviewed according to tasks and this has resulted in a worn out and demotivated workforce. Also, though some of the processes adopted for treatment expansion were meant to simplify access to care, other processes have made access to treatment protracted and caused patients to drop out of care. This becomes counterproductive to the original objectives for the adoption of the global strategies; chapters one and two address this phenomenon. Using the travelling metaphor helps to juxtaposition the challenges that the state encounters in dealing with a guest that has set out from far off to help, and in turning away needed help even though the approach in which the support is given might be incongruous.

## Social navigation theory

Social navigation theory examines how people deal with challenges they encounter in everyday life, and how they act in difficult or uncertain circumstances. Vigh (2009) first coined the concept to elucidate how youth from Guinea-Bissau manoeuvred during the time of civil war. The concept of navigation is very much central in this thesis, as I observed that PLHIV had to do a lot of manoeuvring in light of an HIV diagnosis. Patients that missed appointments, or defaulted, faced the wrath of the counsellors and nurses; they were threatened and told they would die if they did not respect appointments or became non-adherent to the treatment regimen. Moreover, they lost their benefit of getting more than one month's worth of medication at a visit. Patients adopted various strategies to manage such situations, including changing clinics and presenting themselves as new patients in clinics where their transgression was not known.

The study also found that women in long-term relationships were challenged in linking to care in a timely manner due to kinship dynamics (both with spouse and mother-in-law). After diagnosis, they struggled to disclose to their partners, which was required before treatment initiation. They feared being blamed for bringing infection into the relationship and being ostracized. Since they valued their relationship above their own medical needs, they spent considerable time developing strategies to navigate the hurdles they encountered within their social sphere and in the process missed clinic scheduling for care. For example, one of the women was pregnant, and claimed that the pills she was taking were vitamins for the baby; in this way, she concealed the fact that she was taking ARVs. The situation was so delicate for one study participant (as her partner was in denial of her HIV infection and refused to have the family get tested) that she had to be very subtle in her approach; she tuned in to radio programmes on HIV when she and her partner were together, so they both

would learn more about the disease. Over some time, he began to get interested and started to ask questions. After a year, the man finally tested and was immediately initiated onto ART as he was at stage 3. He started ART together with his wife.

Social navigation theory provides a framework to analyse PLHIV's social webs and how these are affected and utilized when they are diagnosed, and it helps us understand what strategies and approaches PLHIV use to manoeuvre through challenges they encounter in the daily lives. When the public health system categorizes PLHIV as dropping out or leaking out of care, lost to follow up or defaulting on treatment, those individuals are actually navigating challenges encountered in their social lives as a result of the infection, which make it difficult to link to care or stay in care within the timelines determined by the biomedical system.

Chapter three explicates how expert clients deal with challenges they face in their job as volunteers. Due to their awkward position in the health care system they do not have room to seek redress for grievances in the workplace. Also, expert clients are a cadre of people with low status, engaged in a job because of their disease, and working in a profession for which they are not academically qualified. They have to deal with power imbalance in the clinic spaces, negotiating and managing relationships with colleagues. In order to cope, many expert clients created bonds with each other that acted as a support system in times of turmoil. Other expert clients opted otherwise, by associating with nurses to be favoured over others.

Social navigation in the thesis is an analytically useful concept as it allows us to capture an alternative perspective on practices and the intersection between agency, social forces, and change. It is an analytical lens through which we can focus on how people move and manage within situations of social flux and change how that is displayed under different

circumstances (Vigh, 2009).

### Therapeutic itineraries

The concept of therapeutic itineraries was first coined by Auge (1985), to focus on the different pathways and journeys that a sufferer explores in a quest for health. It connotes a preference of one therapy over another, as when PLHIV choose another therapeutic path over ART to manage the HIV infection. When some PLHIV dropped out of biomedical ART-focused care, they took part in other forms of care. Dropouts pursued different ways to cope with their infection by trying to maintain longevity, by taking alternative medicines and immune boosters, pursuing spiritual healing, eating healthily, reducing stress levels, and all sorts of other habits to strengthen their immune system. All dropouts encountered in the study indicated that they could be involved in pluralistic therapeutic options to be in optimum health, but once there were signs of health deterioration signalled by a declining CD4 count, the biomedical regimen became the eventual therapy to manage infection. This shows that though PLHIV might drop out of HIV care, they eventually bounce back to the health system. This concept helps us to understand that not all people diagnosed with HIV will accept the medical system at first. Instead of writing off PLHIV who have disappeared from the system, or reprimand them when they bounce back to biomedical care at advanced stages of AIDS, the system needs to have room to expedite the initiation of ART for such clients.

This concept also helps us to appreciate the reasons for a particular choice of therapy and the dynamics that influence choice in the therapeutic process. For some of the PLHIV who dropped out of care or could not enrol to care, it was not an individual decision or even a desired choice to de-link from HIV care. Decisions were influenced by careful consideration of the realities within their social sphere; in other circumstances, significant others in the lives of PLHIV took decisions for them. To elucidate this fact, the first chapter outlines the

itinerary of married women to manage HIV infection. The journey starts at her spouses to disclose her HIV status. Next on the itinerary is her mother-in-law's, to please her, otherwise the mother-in-law can influence the husband against her. Further on the journey is her biological family, which she has to represent well as a good daughter: she must fulfil her filial duty and bring honour to her family so that her marriage thrives; a failed marriage brings shame and stigma to her and her family too. If she returns home, her family cannot afford to take care of her and her children. Therefore, marriage serves as a place of refuge as husbands have to provide for their wives' needs. Unfortunately, social circumstance takes precedence over the biomedical consequences when she has to weigh options whether to follow the advice of the health worker and start HIV treatment or protect her marriage.

Three case studies in this chapter tell a story of a long journey travelled by PLHIV before initiation can ensue. They tell us that PLHIV who leak out of care always have a desire to take the prescribed biomedical route but often do not do so because they have to be emotionally and socially ready in order not to jeopardize their support system. A variety of therapeutic options may be tried and serve as a placeholder in the interim, before biomedical treatment starts. Patients use alternative pathways, which explains the reason for delayed linkage to care after diagnosis, delayed initiation, and treatment refusal, all of which explain the dynamics causing leaks in the continuum of care. By using the therapeutic itinerary concept and the metaphor of detours and roadblocks patients encounter in search of treatment we can gain insight into the numerous points where delays occur before treatment starts. Delays occur at the personal level, kinship level, and institutional level. Ideally, there should be no further delays at the facility level, once patients have navigated all of the other levels. Addressing delays in treatment onset cannot be left at the institutional borderlands of health facilities but must extend to the wider contexts – structural, social, and personal – that give contour to the diverse maps patients follow in their quest for therapy.