Thandeka Dlamini-Simelane:

»Travelling Policies«

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TRAVELLING POLICIES Expanding HIV Treatment



Collage of fieldwork photographs by Thandeka Dlamini-Simelane, Hhohho Region, Swaziland (2022).

The clinic and working tools for expert patients.

"It's been a long journey that started with PLHIV [People living with HIV/AIDS] considered frail people suffering from a debilitating and stigmatizing disease associated with promiscuity and a curse. We were walking tombs because HIV was the final verdict of someone infected with HIV back then. There was nothing valuable about an HIV-infected person. Things were slowly starting to change, and treatment was becoming available, but people were afraid to test and start treatment. People were needed who could give hope and be role models to encourage those who were frightened by the possibility of HIV infection. As more people became ill, including healthcare workers, healthcare facilities were overwhelmed and could not handle the influx of patients. Health facilities set out to find PLHIV who were willing to make their HIV status public and volunteer in clinics and hospitals. Initially, we [LHIV] were sought out, and we were a tight-knit group, new to such an environment, supporting each other. We were given a token of appreciation for our time, in the form of bus tickets, food, visibility materials, hotel nights to attend workshops, etc. The token became something tangible and semi-permanent. Some received a monthly stipend. As a result, the number of people willing to disclose their HIV status in order to enjoy the benefits associated with volunteering skyrocketed. The paradigm changed: PLHIV were no longer sought as volunteers, but strict recruitment procedures were introduced where we had to apply to be selected. Strict performance requirements and undesirable working conditions were imposed on those who were offered the jobs. The clinic space that was sought after by many to contribute to the HIV response, soon became a breeding ground for frictions among PLHIV, with nurses and other support staff. Being there was a matter of survival and obligation, rather than out of love to serve."

Interview with Ntazo, an expert patient, Swaziland (2013).

Ntazo is an expert patient. Expert patients refer to people that live with HIV (PLHIV) that work in health facilities, performing duties delegated by nurses. The drive by UNAIDS and WHO for patient-centered care meant patients' wishes should become the focus of care delivery. Their skills, knowledge, and information had to be considered in the management of chronic diseases, such as HIV. These principles are from the task-shifting strategy and

greater involvement of people with AIDS (GIPA). In this article, I highlight how travelling global HIV policies and strategies (such as task shifting and GIPA) are reconfiguring established care practices and workplace dynamics in health facilities in resource-poor settings like Swaziland. Task shifting and GIPA are examples of travelling policies, used metaphorically to depict their origin from boardrooms in UN headquarters in Geneva and New York and their movement to high-disease burden countries of the South such as Swaziland to guide the HIV response. Furthermore, I explore how patients qualified through infection are used to closing a critical human resource gap and how this imbroglio plays out in everyday life. I also describe the translation process and the unintended consequences beyond the clinic that affect everyday life. I focus on the baggage of the travelling concepts and policies,[1] elucidating how such baggage potentially worsens the fragility of ailing public health systems and harms established structures used for coping with distress within a community.

TRAVELLING POLICIES Radical Treatment Expansion

The concept of the expert patient was first developed in the global North, particularly in the USA and the UK. It helps improve the quality of life of patients with long-term conditions by developing self-management skills, increasing patients' confidence and motivation to take control of their lives, and supporting other patients with chronic diseases.[2] The UN-WHO adopted the concept and described it as a task-shifting strategy to be implemented in resource-poor settings, primarily through the use of expert patients to avoid health worker shortages. In African settings, PLHIV were used to demonstrate the effectiveness of antiretroviral therapy (ART), promote patient adherence to HIV treatment, and demonstrate in a pragmatic way that ART offers a second chance at a long, healthy life.[3] In addition, adapting this concept facilitated greater involvement of people living with AIDS which became known as the GIPA principle, which UNAIDS was already pushing to strengthen HIV response. GIPA is a set of principles that pronounce rights and responsibilities of PLHIV and how they can enhance quality and effectiveness of the response to HIV. In Swaziland, PLHIV working in health facilities are referred to as expert patients, which is a local form of the GIPA. As PLHIV became expert patients in clinics, they became adepts in taking treatment, provided counselling of HIV treatment, and expanded experiential knowledge of living with HIV: how to resolve everyday challenges of living with the disease and with ART treatment.[4]

As PLHIV became increasingly involved in the delivery of care in Swaziland, new relationship dynamics and norms were reconfigured among health care workers and the new cadre of expert patients.

In this paper, I draw from a rich scholarship on voluntarism related to health care in Africa. Sometimes volunteerism is motivated by economic benefits,[5] while in other cases it provides an opportunity for personal development or recognition in society. In Ethiopia and Mozambique, socio-moral values drive people to volunteer.[6] Other studies focused on power dynamics and disputes between expert patients and nurses in clinical settings. I illustrate the different (therapeutic) practices and relationships that emerge when expert patients are the frontline workers in the delivery of HIV care in clinics in Swaziland. In Swaziland, the expert patient program was launched in 2006. When I conducted fieldwork in 2011, clinics had just begun to expand their service delivery to prepare for treatment scale-up. Clinics were transitioning from providing basic HIV services such as HIV testing to managing minilabs for

point-of-care diagnostics, enrolling patients into HIV treatment, and tracking patients to monitor adherence. This created a demand to encourage people to get tested for HIV early to survive the disease. As a consequence, the demand for services increased exponentially and conventional health workers alone could not manage the influx of patients.

"I had been on HIV treatment for two years when the nurse in the clinic told me that they will be recruiting PLHIV who are taking ART the right way and have no obvious symptoms that they are sick. At that time, my adherence levels were so high that I was given meds for two months. Furthermore, the incumbent needed to be able to speak and write in English with good interpersonal skills. She said I fit the criteria and informed me that she recommended my name for the position. It wasn't long before I was offered the position. The Ministry of Health pleaded with the public to support the HIV response and was anchored by the King's call to the nation to contribute in some way towards the fight against HIV. I have been doing this job for six years now. I was told my main duty was to provide counselling to people that refuse to test and other menial tasks assigned by the nurses."

Interview with Ndumi, Swaziland (2013).

When the expert client program started, nurses' recommendations of adhering to ART patients were the predominant form of becoming an expert patient. During the study period, PLHIV had to apply and compete for expert patient positions. However, as treatment programs expanded and demand for expert patients soared, requirements changed and became stringent: requirements now included not only formal criteria such as a high school degree and a non-judgmental attitude towards HIV patients. They also included skills such as the ability to demonstrate a high level of care for others, impartiality for vulnerable individuals, and a commitment to working within the HIV field and a good reputation in the community.

Norms for expert patients were set by external funders who drove the HIV treatment expansion agenda in the country.

TRAVELLING POLICIES Everyday Work

"It's 7.30 a.m., and patients are streaming into the clinic to get ahead of the queue. You can quickly spot burgundy suits dotted in the crowds. They are expert patients who are also rushing into the clinic, but for completely different reasons. They need to be at their workstations before 8 a.m. to scrub floors, organise patient queues, and take out patient files scheduled for the day. This must be done before 8 a.m. or the day will be a disaster for the expert patients because picking the files out of the haystack when the patient is in front of you is time-consuming. The first exercise is patient care: Weighing, counting pills, counselling. Adherence counselling is tedious because you are dealing with people who are not cooperative. For those who don't default, counselling is equally arduous because they may be dealing with side effects or social problems that affect their willingness to take treatment. While an expert client is counselling, he or she may run out of medications, which they have to package according to the monthly rations that patients receive. This means leaving the workstation and abandon patients to fill the bottles, counting the pills one by one to make sure they have the right amount in them. Then you're done with the patient and move the remaining line along. The rest of the medicines in the clinic are packed by pharmacist assistants, who refuse to pack ARVs because everything related to HIV including medicines are perceived as tasks of expert patients."

Entry from Thandeka Dlamini-Simelane's field diary, Swaziland (2014).

It would be easy to assume that expert patients were full-time clinic staff, but they were volunteers who helped the nurses. They received only inconsistent, meagre compensation for their time. They worked five days a week and eight hours a day. Originally, they were to perform counselling duties, encourage people to test, keep them in treatment, and help those who stopped taking treatment to get on the right track. However, in their everyday practice, the expert patients did much more. Yet their attitude as volunteers did not change. During my fieldwork, expert patients began to take on the main tasks that required training to acquire skills.

Expert patients learnt these skills while working with nurses on a daily basis.

As a result, the scope of the work grew. Some of the tasks were quite technical for a layperson, such as taking vital signs and operating computers to electronically record medical data in the system. They also had to interpret lab results for patients, and educate patients about managing the side effects of treatment, by using their experiential knowledge of living with HIV. The usual procedures in the clinic had to be changed when it concerned expert patients. It is the duty of the orderlies to clean the entire clinic, but they refused to clean the workstations of the expert patients. Medications are packaged for all departments in the clinic, but the pharmacist did not pack ARVs. I even saw expert patients that brought their own coffee, tea, sugar and cutlery, even though all the staff was taken care of. The repertoire of professionals' engagement in the HIV response is not all bleak. Although the disease served to qualify them for work in health facilities, which was accompanied by a difficult work ethic, joy was also experienced in the midst of uncertainty. Through chats with expert patients and daily observations, I learned many intimate details about their lives, both inside and outside of work, as daily conversations and goodbyes were commonplace. I witnessed both frustrating and exhilarating moments of their work.

Expert patients complained about exploitation, irregular payment, or stigma. They also demonstrated great perseverance in performing their jobs and overcoming difficult work environments.

I saw how tenacity and despair, diligence and reverence of superiors sometimes led to their exploitation. Over the years, the struggles that expert patients endured, evolved drastically. For instance, there were more instances of shedding tears and sad moments because of stigma, and worrisome moments due to inconsistency of stipend payment. Now expert patients feel secure in their job and excited to execute their duties regardless of challenges because they have managed to cut their niche in the clinic spaces. For such reasons, gratitude is prevalent as their job gives new meaning to their lives. Becoming role models for other patients and being useful from being frail and dependent and ability to support their livelihoods.

In the midst of precarity and lack, using their sick bodies to secure a livelihood was the only available opportunity to survive.

TRAVELLING POLICIES Affective Ties

"It's lunchtime, and everything comes to a halt in the clinic, as everyone has to take a break and grab a bite to eat before summing up the day's activities. It's a norm in the clinic for everyone to take a lunch box to work. Expert patients usually took their lunch on their desks because there was no place for them to sit or there was simply no way to mingle and eat with the rest of the staff. First, the lunchbox gave away the quality of the food they ate at home, as it was usually leftovers from dinner. Due to their low economic status, the quality of food eaten by expert patients was low. Therefore, it was not uncommon for expert patients to share their food; one person would bring starch, such as bread, and the other would bring vegetables or fruits such as avocadoes to share. Or one might bring sugar, the other tea. In the summer, they shared fresh produce such as corn and pumpkins. Sharing food strengthened the relationship between the expert patients and it was way to see which expert patients were friends and which ones were not."

Entry from Thandeka Dlamini-Simelane's field diary, Swaziland (2013).

There was a higher degree of closeness amongst expert patients than any other group of clinic staff. Expert patients used the affectionate term *bahlobobetfu* to refer to peers with whom they got along well. In SiSwati, it means a reliable person, especially in difficult times. The term has a pleasant connotation and represents a certain bond and a reciprocal relationship that is often the basis for their connection. For this reason, expert patients would not refer to nurses as *bahlobobetfu*, but rather as bosses.

"Once, the senior nurse called into her office and scolded me for treating a client badly. She was judgmental without even asking to hear my side. What hurt me most was that I wasn't even the one the client was complaining about, but the expert patient she was friends with. I was very hurt, but there was nothing I could do. I told Muhle [another expert patient]; she comforted me. She was really a great support to help me deal with it. In fact, as expert patients, we are our mutual support system. When we have problems, we share them with each other, cry it out, and comfort each other. Then we get back to work. We are like a family."

Focus Group Discussion with expert patients, Swaziland (2014).

In the absence of a structure for sharing grievances and complaints, expert patients found an effective way to cope with the stress of their jobs by supporting each other during challenging times, as Linda's story shows. Instead of turning to their superiors with their concerns, expert patients preferred to seek comfort from others. Consequently, expert patients were generally closer to each other than to the rest of the clinic staff. Those who worked in the same clinic seemed particularly close. All expert patients I spoke with agreed that the shared infection strengthened their bonds. They also supported one another when they had an emergency that required them to miss work or leave work early.

"The fact that we are known as HIV-positive employees in the clinic creates cohesion and solidarity between us. Our HIV unites us because we are the only people in the facility who got a job through the disease."

Focus Group Discussion with expert patients, Swaziland (2014).

"We simply ask *bahlobobetfu* to cover up or help with an extra task. [...] [When] I come with a problem from home, before we start work for the day, I call my peers and we talk about it."

Focus Group Discussion with expert patients, Swaziland (2014).

The trust and connection that was built were like a buddy system, not only for professional challenges but also for problems in their personal lives. The closeness shared by the expert patients and the support they gave each other was also used to mediate conflict between peers, reminding each other of their roles and the need for unity. This support network was not utilized by all; some expert patients resorted to other support systems to manage their work.

TRAVELLING POLICIES Conflictual Relations

In contrast to the affective ties amongst expert patients, I noted an ongoing subtle feud between expert patients and other support staff, especially the orderlies. Fundzi, who has been an expert patient for six years, recounted her experience:

"I cried all the time [because] the support staff [orderlies and janitors] forbade me to use the utensils and cups in the clinic. Also, I was not allowed to sit in the kitchen anymore because the nurse told me that we were not allowed to share the utensils with the nurses. I felt stigmatized."

Focus Group Discussion with expert patients, Swaziland (2014).

When Fundzi started working, she was destitute and could not even afford her own cutlery. The expert patients accused the orderly of mistreating her through stigmatization and exclusion. Nana, a woman who has been an expert patient for four years, also shared her experiences with a nurse:

"The nurse in our clinic refused to clean our workstations, saying she was hired to clean the offices for the staff. [...] She said she didn't understand why we couldn't do it ourselves because we were uneducated like her, that's what uneducated people do."

Interview with Nana, Swaziland (2014).

The treatment of the expert patients by the nurses seemed to be motivated by resentment, partly because they shared the same space in the clinic, but perhaps also because they had similar social status. Apparently, as full-time government employees, the orderlies felt superior to the expert patients who only had a temporary contract. These actions served to remind the expert patients that they were the lowest rank in the clinic's hierarchy. One could also interpret the friction between nurses and expert patients as a reflection of the fact that nurses were not targeted by HIV workplace programs that sensitize health workers on discrimination amongst themselves. As the patient's statements suggest, it is also possible that clinic staff viewed expert patients likely to infect them with HIV.
Expert patients also described conflicts with nurses. In clinics where nurses were reportedly hostile, expert patients also complained of harsh treatment by nurses, suggesting that other staff mimicked nurses' behaviour toward expert patients. In these clinics, where nurses provided less support and tolerated mistreatment, expert patients were less enthusiastic and complained more about the volume of work.

"In our clinic, we are like one big family. We often hear colleagues [expert patients from other clinics] complaining about mistreatment by nurses or other staff, but not in our clinic. We always hold meetings to discuss problems, and Umphatsi [our boss] makes sure that if there are complaints or problems from staff, not just expert patients, they are dealt with accordingly."

Focus Group Discussion with expert patients, Swaziland (2014).

The opposite was also true: where nursing staff were supportive, expert patients did not report mistreatment by other staff. Expert patients had healthier relations with all staff and were less likely to complain about their work, except for a frequent complaint about low pay, although the expansion of duties was characteristic of all clinics. In clinics with strong leadership, there was less friction between staff and expert patients. In clinics where support staff were hostile towards expert patients, nurses were quick to respond.

TRAVELLING POLICIES Threatened Solidarity

While many expert patients maintained strong bonds and supportive peer relationships, there were also exceptions as friction arose between them. Some separated from their closest associates and were seen as renegades for causing division. These included those who were allied with the nurses or full-time staff, but not with their colleagues. They were considered 'sell-outs' and were not part of the expert patient group. Although the expert patients did not actively discourage their peers from having relationships with other staff, they were implicitly expected to be loyal to each other. Those who were closer to other staff were considered untrustworthy and their loyalty dubious. In addition to being considered disloyal, they were also accused of being slothful in their duties and diligent towards the bosses' requests as their major priority was the nurses' private errands, and the nurses reciprocated by bailing them out when needed. Another source of friction among the expert patients was the difference in stipend levels.

"It would be better if all expert patients could receive the same amount of stipend."

Interview with Vuma, Swaziland (2014).

"In fact, we do much more work compared to expert patients from other programmes. We take care of pregnant and TB patients."

Interview with Phinda, Swaziland (2014).

"We have similar skills and training – so why the difference in the stipend amount?"

Interview with Sethu, Swaziland (2014).

Expert patients were paid different amounts directly by different donors. Such a scenario had harmful repercussions and caused disparities in the scope of their work and stipends received. Unequal pay contributed immensely towards creating divisions among expert patients. Moreover, expert patients competed and bragged about belonging to a donor considered rich. The 'rich donor' was the one who paid the expert patients a higher stipend, had flashy cars, and owned assets in the clinic. I call this feud among expert patients over assets, donarization.

"Sometimes we can even quarrel over stationery or furniture – imagine what happens if your donor is the poorer one."

Interview with Ngeti, Swaziland (2013).

The expert patients positioned themselves as stewards of their donor's assets. For example, if one wanted to borrow a pen or chair, the expert client whose donor had donated the stationery might respond: 'Ask your donor to buy it for you'. Expert patients whose stipend was paid for by a wealthy donor seemed having more power over their fellow patients. Donorization implied that relationships were becoming unstable, cohesion within the group dissipating and a crack started. Needless to say, expert patients were concerned when these traits stuck out among them, challenging solidarity known to prevail among PLHIV.

TRAVELLING POLICIES Unintended Consequences

When the promoted travelling policies are implemented in the locale,[7] they leave far more complex traces beyond programmatic outcomes in health facilities. GIPA and task shifting not only resolved human resource shortages and contributed to HIV treatment expansion but also had unintended consequences beyond the clinic space. They leave a trail in the public health systems, consequently, the structures are weakened further, and structural violence becomes rife as the underprivileged become a bailout and suffer the most brunt. The article is an exposé of the feuding among PLHIV and the consequences of the inclusion of expert patients as an informal cadre into the healthcare system.

The article is an exposé of the feuding among PLHIV and the consequences of the inclusion of expert patients as an informal cadre into the healthcare system.

It explicates the complex resonances and dissonances that arise when PLHIV are involved in frontline health care service delivery, explores relational dynamics developed and illuminates the challenges faced by expert patients as they fulfil their roles. The repertoire of patients' engagement in the HIV response is not all bleak. Although the disease served to qualify them for work in health facilities, which was accompanied by a difficult work ethic, joy was also experienced in the midst of uncertainty. From debilitated people with a terminal illness who were stigmatized, they have become role models among PLHIV. They are grateful for the second chance at life that ART offers them and for the opportunity to raise their children and

make a living.[8] Due to a lack of state funding, the expert client programme was externally funded, giving outside actors influence over the administration of the programme and weakening the state's role in directing the health discourse of its citizens.[9] Expert patients had different contracts which triggered territorialism and donorization that threatened existing solidarity and undermined the mutual support that expert patients enjoyed. Togetherness was replaced by the pursuit of individual gain and power over others. Limited resources in resource-poor settings force makeshift development arrangements to become the mainstay approach. Increased involvement of PLHIV in frontline service delivery in health facilities also weakened the solidarity that was prevalent among PLHIV. Earlier work portrayed PLHIV as a community of disease sufferers with strong collective efforts and enjoyed solidarity which led to the achievement of great milestones globally.[10] In Swaziland, the public health system is weak and so are the accountability structures. Precarity in clinics in the study facilitated prejudice to thrive. The kindness of superiors, great leadership skills, or sucking up to superiors become the only available options to protect the vulnerable from predatory practices. In instances where a nurse had good leadership and management skills, expert patients were generally motivated and there was less conflict and the reverse is true. Where nurses interacted poorly with patients, there was a high probability that expert patients also offered poor-quality services. In this quotient, one fact shines brightest: nurses and overall administration were the catalysts that determined whether the inclusion of expert patients in service delivery was both programmatically effective and rewarding for all health care facility staff.

As a result of the radical expansion efforts of treatment programs, staff welfare is at risk of being overlooked. Manipulation of underprivileged citizens thrive. This is the form of radicalism that ensues when resources are scarce.

When globally derived strategies are implemented in locales, the translation process plays out differently from the intended outcome. It is an intersection where the desperation to end AIDS by involving patients as a solution, conflates and conflicts with ethics, culture and politics. The seemingly insurmountable challenge of the acute shortage of health workers was instantaneously resolved by GIPA as a magic bullet. These were drastic and radical measures adopted to ensure treatment reaches all in the hardest hit, resource-limited settings of the world. The globalisation process, that is the local adaptation of global policies and strategies such as task shifting, need to be explored beyond the binary perspectives of its programmatic relevance and effectiveness. Equally important is to understand how global policies for treatment expansion may invade a society and how they can hamper, alter or configure new practices, shape norms and meanings and affect social processes. This is the baggage that travelling health policies from the North bring to the countries in the South.

Notes

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Further Readings

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