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

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CHAPTER 6

HIV Treatment Concepts ‘Lost in Transition’: The case of GIPA Concept Adoption and Engagement of Expert Clients in Swaziland

Accepted but not published: Dlamini-Simelane, Thandeka. HIV Treatment Concepts ‘Lost in Transition’: The case of GIPA Concept Adoption and use of Expert Clients in Swaziland. *Anthropology in Action*

Abstract

Following the call by Joint United Nations Programme on HIV/AIDS (UNAIDS) in 2006 to involve PLHIV in treatment programmes, expert clients were recruited to provide services within healthcare settings as volunteer alongside paid health workers. Swazi law requires that anyone working on a full-time capacity for three months must have an employment contract, complicating the status of expert clients. This paper traces the genesis of the volunteer framework used to engage PLHIV in the provision of HIV care in Swaziland and describes how the quest for PLHIV to be involved coupled with donors' promotion of the GIPA principle have together resulted in PLHIV serving as low-cost workers, disempowering the very people GIPA was meant to empower. Lastly, we call for review of GIPA-based policies and a paradigm shift regarding non-medically trained cadre of workers of in an era of acute health worker shortages in resource-limited countries hard-hit by HIV.

Introduction

As I sit in the waiting area outside an HIV counselling room in a rural clinic in Swaziland, many people walk in and out – young and old, frail and agile. Some enter the counselling room looking distraught and leave with cheer and in good spirits; after being worried for so long, they finally know what is wrong with them and how to manage their condition. In the counselling room, they have encountered someone who lives with HIV and has successfully managed the same sickness from which they suffer. They find a role model, someone who understands what they are going through, who will not judge them. This person is an expert client. I observed that expert clients had a fundamental role in service delivery, serving as the bookends in the continuum of care, albeit as volunteers. They filled a big gap in care: it seemed without them, the ART programme could barely survive as none of the existing clinical staff, nurses or doctors, had time to execute the tasks they performed.

As part of fieldwork, I was based in clinic settings and worked with expert clients for more than four months. I observed their diligence performing duties and saw with my eyes the number of tasks they were expected to perform. To start with, the official working hours for all clinic staff (full time) was 8 am to 4pm. However, I noticed that expert clients usually started work before 8am, and left after 3pm when they are supposed to finish at 3pm. Expert clients worked longer hours for a variety of reasons; to prepare files for clients who have an appointment for the next day and to get patient files from overcrowded lockers. Therefore, coming early was necessary so that they can plan for the day accordingly and put patient files aside before clients come which helped to expedite the work since expert clients had many clients to deal with on a daily basis.

Expert clients ECs had to see more clients than they reasonably can in a day; they attended

at least 15 and sometimes as many as 60 clients on a busy day, particularly on Mondays and the first and last week of the month. An expert client is the first person a patient sees before their journey in the HIV continuum of care begins. A patient that tests HIV positive has to undergo seven critical steps on the day of diagnosis. The expert client is involved in all steps except staging and dispensing prophylaxis.

During *pre-test counselling*, expert clients explain what it means to know one's HIV status and why it is important. At the *laboratory*, the expert client orders lab tests (HIV test or CD4 count) for the clients by filling in lab request forms and recording the results in the register. During *post-test counselling*, expert clients disclose test results, discuss how to cope with a positive diagnosis, and explain the treatment trajectory. The heftiest part of expert clients' job is *chronic care enrolment*, which involves opening a file for HIV-positive patients. The expert client elicits and records the patient's physical address, demographic data, anthropometric data such as height and weight, and does a psychological assessment to gauge the patient's readiness for lifetime commitment to HIV treatment. All this information must be accurately entered in different registers. Also, expert clients complete a client health card, which is a medical record that the patient keeps. Finally, during *adherence counselling*, expert clients prepare patients to understand what is involved in taking treatment for life. The paperwork at this stage is also intensive, includes pill counts and booking clients for follow-up appointments.

As I observed them perform the scope of work as volunteers, I embarked on my own hermeneutic journey (Van der Geest 2002: 5) I wondered how expert clients providing such a critical role and actors in service delivery were engaged as volunteers instead of an institutionalized workforce? What was the Ministry of Health's position on this situation? Did the ministry see it as an anomaly at all that expert clients performed core duties for

nurses as volunteers and the impact it might have on the overall health outcomes? And what was the perspective of PLHIV organizations about the volunteerism framework used to engage PLHIV in service delivery? I set out to understand how this came to be. At a personal level, I pondered if I could work with the same diligence expert clients exuded given the voluntarism framework they worked under.

Hence, this article attempts to address such questions that emanated from reflexivity and preoccupied me as events that played during fieldwork. The ethnographic approach facilitated extensive immersion in the intricate everyday roles of expert clients. I witnessed the challenges they encounter and how they manoeuvre around them. This type of involvement provided rich data over extended periods, elicited not only from spoken words but from the gold standard of anthropological methods, participant observation (Davies 2008: 68). It allowed me to engage with the interlocutors in detail that I had to continuously step in and out of different roles during fieldwork. In the paper, I describe the transition of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle in theory and practise; how a non-medically trained cadre ended up doing so much work without their position becoming institutionalised and how this principle has been misappropriated and led to PLHIV being engaged as low-cost labourers. I show that PLHIV activism for involvement at the beginning of the HIV pandemic inadvertently sowed the seeds for PLHIV becoming a cheap work force option. May and Finch (2009) in the theory of normalization describe how practices become routinely embedded in everyday life. Likewise, this paper is about how and why expert clients became a low-cost option to solve human resource shortages and how such a paradigm was normalized. In current HIV programmes, GIPA is mutating itself in various forms thus disempowering PLHIV that it intended to empower. At the overarching level, I will be looking at the tensions and frictions between public health and individual rights, using expert clients in

Swaziland as a case study.

Methods

Study Setting

I conducted this research in Swaziland within intervention sites for the Maximizing ART for zero new infections (MaxART) project, which aimed to achieve universal access to ART by removing barriers, gathering experiences of ART eligible patients and modelling ART as prevention of new HIV infections. I collected ethnographic data in two clinics, spanning over thirty months, between June 2012 and December 2014. I spent two full months in each clinic, and the rest of the period I visited the clinics intermittently, each time for a week or two. The clinics were selected because they had high patient volume. One was in a typical rural area whilst the other was on the periphery of the capital city of Mbabane. This difference allowed for a contrast in patient experiences around access to services, as physical access differs between rural and urban areas. Both are government-owned community clinics, and heavily dependent on external funding to expand ART. Donors fund staff salaries, equipment and provide expertise and mentorship. I positioned myself within the pre-ART treatment phase to analyse health system threats and barriers to treatment, and the actors involved therein.

Interviews and Observations

I conducted observation during sit-ins in the counselling room, and helped expert clients file patient records, weigh patients and record patient data in the registers. I conducted twenty-four in-depth interviews with officials from the Ministry of Health and representatives from PLHIV organisations to understand the historical context of engaging expert clients as volunteers, and how and why this model has endured over the years. I had numerous informal conversations with expert clients and nurses, and observed and overheard many patients' conversations. These informal conversations helped to elicit

health workers' perspectives of expert clients as a cadre, their role, and their status in the clinic. I also participated in six biannual meetings of the MaxART programme where seven partnering organisations (five international and two local) convened to discuss the progress and challenges of the project, and observed power interplays between the local and the international partners in the various national dialogues. Furthermore, during these meetings, I observed the scope of involvement and engagement of representatives from the PLHIV network, the focus of their activism, and their tactics.

Data Analysis

Interviews were conducted in the vernacular language, siSwati, and in English, and transcribed. Field notes from observations were recorded in notebooks, whilst interviews were audio recorded. Analysis was an iterative process during fieldwork, for every new dataset. In order to identify themes transcripts and field notes were read repeatedly. Themes that emerged from the observational data were noted and included for subsequent interviews or to trigger informal conversations. NVivo was used for content analysis when data collection was completed to identify recurring and overarching themes.

Ethical Approval

The research was cleared by the ethics board of the University of Amsterdam and the Swaziland Research Ethics Board. The head of the Swaziland National AIDS programme [SNAP] gave written permission for entry to each clinic. Expert clients were routinely members of the wider MaxART consortium, hence routinely interviewed and as such written consent was not necessary. As a result, only verbal consent was obtained.

Expert Clients and Evolution of GIPA in Swaziland

What is an expert client?

According to the Ministry of Health's expert client training manual, an expert client is a person living with HIV (PLHIV) and taking antiretroviral therapy (ART), who has modelled compliant behaviour in taking HIV treatment, lives a *normal* life despite infection, and works within health facilities as a health worker to provide counselling to PLHIV, bring hope and encourage them that a healthy life with HIV and ART was possible. Expert clients in research sites were full time counsellors and did more duties outside of counselling in health facilities they were based. In the research, nurses no longer provided HIV counselling. That role is carried out primarily by expert clients who form the cornerstone of expert client involvement in delivery of HIV services according to the job description from the Ministry of Health. However, over the years the task of expert clients has evolved. They now perform such mundane tasks as enrolling patients into HIV care, tracking ART patients and booking patient appointments.

Once hired, Swazi expert clients are prepared for their role in HIV service delivery through six-and-a-half-day training, followed by a two-day practicum in a care and treatment site. In Swaziland, there are expert clients that focus on antenatal care whilst others work exclusively in ART clinics. Regardless of the program in which they work, they are trained together on a quarterly basis by funding partners which implement HIV programmes in Swaziland. The training of expert clients consists of modules in the curriculum inclusive of the following; introduction to HIV, HIV basics, paediatrics and HIV, impact of HIV, role of expert clients, communication and counselling skills, HIV care and treatment, adherence to treatment, stigma and disclosure, positive living, record keeping, referrals, facility-community linkages and a practicum. In the clinic setting where

I conducted research, expert clients report to the nurse-in-charge. The reporting arrangements for expert clients differ in healthcare settings such as hospitals or health centres.

Human Resources for Health Situation in Swaziland before GIPA

The first organizing of people with HIV dates back to 1983 in the US, when HIV-positive gay men convened in Denver to demand non-discriminatory treatment of PLHIV (Advisory Committee of the People with AIDS 1983; Wright 2013). Their demands were summarised in a document called the ‘Denver Principles’, which outlined the rights and responsibilities of PLHIV. This action birthed the Greater Involvement of People with AIDS (GIPA) principles. Later on, donors embraced and promoted the GIPA principles and made involvement of PLHIV representations a core requisite for organization to receive funding (Morolake et al. 2009). In Swaziland, a shortage of health workers resulted in the adoption of the expert client concept within biomedical spaces to expand the workforce through PLHIV.

In 2004, when ART became freely available in Swaziland, (Kober and Van Damme 2006) documented the dire human resource situation in Swaziland: 44% of physician posts, 19% of nursing posts, and 17% of nursing assistant posts were vacant and the annual output of 80 newly trained nurses was not enough to meet demands created by ART availability. This situation was compounded by a 40% reduction of nurses, due to HIV deaths. Expert clients were adopted into the health system in Swaziland in 2007 and resulted to improved human resource situation within a few years.

From General Engagement to Provision of Institutionalized Care

Prior to the introduction of expert clients in Swaziland, PLHIV were involved in various capacities in the epidemic response. PLHIV conducted health talks within their communities, encouraged people to test, and participated in policy making and HIV-related research. This helped to reduce stigma and reverse notions about the fatality of HIV. A Swaziland network of PLHIV (SWANEPHA) was established in 2004, merging three organisations: Swaziland AIDS Support Organization, Swaziland Positive Living, and Women Together.⁵ Soon after its formation, PLHIV involvement was wise and more visible. Support groups were scattered throughout the country as PLHIV convened to share experiences, victory stories, and encourage others to know their status. Some PLHIV approached health facilities to volunteer their services.

The inspiration for PLHIV visibility and involvement came from various sources. The first international AIDS conference in a developing country was held in neighbouring South Africa, in 2000. Its theme was 'breaking the silence'. PLHIV were encouraged to become involved.⁶ At about the same time in 1999, Swaziland's King Mswati III declared HIV a national disaster. The presence of the epidemic in Swaziland was clear. With a high HIV prevalence rate, more than 50,000 Swazi adults and children dead due to AIDS, and funerals taking place every day of the week, the situation was overwhelming. The King's declaration took centre stage in his speech at the 2000 opening of Parliament. Specifically, he appealed for support from those with knowledge to educate others about the disease. Moreover, he requested that everybody show compassion towards those affected, encourage them, and spread messages of hope (NERCHA, 2000). With the royal throne

⁵ www.swannepha.org.sz

⁶ www.actupny.org/reports/durban.html

sounding *inyandzaleyo*⁷ [a battle cry] to all citizens, it meant everyone had to join the fight. From the King's plea, there were specific roles only PLHIV could perform, such as sharing information about living with disease and providing encouragement to others living with HIV.

The synopsis above shows circumstances that led to the initial involvement of PLHIV outside of biomedical care. The availability of ART led to expansion of tasks within health facilities. Doctors had to be innovative to meet the increasing demand for ART services.

A doctor who had worked in the ART department of the national referral hospital when PLHIV started to volunteer in healthcare had this to say,

In lieu of increasing duties, as doctors we evaluated tasks that could be delegated to nurses. Shortly afterwards, we realized that as we delegated tasks to the nurses, they were getting overwhelmed. Around that time, PLHIV had started to volunteer services in the health facilities too. PLHIV held health talks, and encourage others to test. We realized that as PLHIV led the health talks and disclosing their status, testing rates improved. PLHIV slowly became immersed in the activities of the hospital and PLHIV were happy to provide their services. Gradually, PLHIV started taking up menial tasks too (Interview, December 2014).

As doctors shifted tasks to nurses, nurses too needed relief and delegated duties. PLHIV who were already at health facilities out of their own volition were willing to take over

⁷ This term in siSwati, the local language, is what someone might call out when if they are in desperate need of help, usually in a life-threatening situation. For example, it is used when one has experienced a robbery or an attack, in order to alert other people to come to the rescue.

tasks. Health workers facilitated PLHIV involvement within clinics.

The call for adoption of task shifting to expand treatment (WHO 2006) intensified GIPA involvement in provision of biomedical care. Swaziland attempted to formalise GIPA via a task-shifting policy in 2007. However, the process stalled and the policy remains in draft form to date. When asked about the rationale for the policy to remain draft, a Ministry of Health official stated that ‘development and adoption of policy in the country generally takes a long time to finalize. Waiting for the policy was going to slow down the adoption of GIPA principles and ultimately the response. The policy intended to review the scope of nursing practice and specify the tasks to be shifted from doctors to nurses and from nurses to laypersons. Even without a policy in place, the urgency of saving lives took precedence and task-shifting occurred without a clear policy.

In view of the possible delays that will be caused by waiting for a policy to be in place, funding agencies in Swaziland suggested to government to implement task shifting under the auspices of the National Health Policy, as it had provisions for universal access to health and the country being signatory to international conventions and global commitments to respond to HIV were used to justify the adoption of task shifting. As one national-level Ministry of Health official explained, ‘This was done in the interest of the public good. We could not wait for the policy whilst multitudes were dying’ (interview, December, 2014). That circumvented the development of a comprehensive policy; instead instruments describing the new scope of nurses’ tasks and an expert client training manual were developed.

This set a precedent. Today, new global ART policies, guidelines, and interventions are not adopted through the set-out route for adopting new policies or process. Rather, new strategies are discussed and agreed at the ‘technical working group’ (TWG) level. A

technical working group tracks and ensures the NSF targets are reached. It has representatives from all of the partners who fund and implement interventions supporting ART uptake in Swaziland, headed by the Ministry of Health. To date, this forum is used to introduce innovations, recommendations to HIV response, and strategies for treatment expansion. Decisions taken in the technical working group are binding for all partners.

Findings

Tracing the Volunteerism Framework for GIPA in Swaziland

When WHO's call for PLHIV involvement in 2006 came out, the Ministry of Health called PLHIV organizations to a meeting to inform them of the GIPA Principle to discuss how they can work together. I sought insight from PLHIV on what transpired in the meeting with Ministry of Health when their involvement was officially requested. We discussed how decisions were made, who was involved, what circumstances warranted PLHIV providing free labour in health facilities and how such decisions about staffing the programme were made. One of the men I spoke with had more than 15 years of experience working with PLHIV organizations and was amongst the first cadre to be involved in task shifting said;

Yes, the Ministry of Health called us to a meeting, *batsi inyandzaleyo* [with a battle cry], repeating the king's words when he opened Parliament, and asked us to be involved. Back then, many people were dying of AIDS. The priority at that time was to save the perishing Swazi nation and join hands with the government. HIV was a well-kept secret and a disgrace, few PLHIV disclosed their status. We agreed to help; it was just a sort of formality because some of our members were already working in facilities. The ministry told us not to expect pay, because there was no money yet, we were to get *imali yensipho* [a minimal amount as a token of

appreciation]. At that time our involvement was purely on a volunteer basis, with limited scope, facilitating during workshops and doing motivational talks. SWANEPHA was new, an organised group of people sharing a disease, trying to find footing and establish itself as a voice for PLHIV. The capacity to advocate was achieved over time, whilst wrong practices were normalized with no one to hold accountable, which continues to this day (Interview, December 2014).

Both parties mutually agreed to work together, none of this was formalised. Though PLHIV were consulted before adopting task shifting, it appears the meeting was skewed heavily towards the Ministry of Health asking for help and not the reverse, PLHIV inquiring about their compensation in the process. Just as the original GIPA Principle envisioned a limited involvement of PLHIV in the form of talks and participation in policy making, a similar scope was probably imagined by PLHIV when they agreed to support the State. The extent of treatment expansion and scope of involvement was yet to unfold. Also, in that state of emergency, PLHIV did not confront pertinent issues, even though it was obvious that PLHIV were taking on an important role.

Another issue that emerged during this interview was how SWANEPHA's initial coordinating role was taken away from them. He further narrated,

CHAI [Clinton Health Access Initiative] was the first funder of expert clients, and the coordinator was one of us, a PLHIV. This was good for many reasons – it was someone who understood the issues we encountered. It was easy to report to the Ministry of Health feedback from the expert clients and the Ministry dealt with issues promptly. However, CHAI funding ran out, and the International Centre for AIDS Care and Treatment Programs (ICAP) took over. ICAP brought their staff as the expert client coordinator. This is where it all went wrong. We lost the power to

hold anyone accountable, ICAP as a funder was not within our sphere of influence (interview, December 2014).

The failure of the State to fund the programme was a fundamental factor in the exploitation of PLHIV services, as it impeded demand for accountability, yet SWANEPHA also lacked the organisational capacity to hold donors accountable.

Perceptions on Experiential Expertise

In Swaziland, GIPA-related efforts are funded through aid agencies ICAP, the Global Fund, the Clinton Health Access Initiative (CHAI), World Vision, Médecins Sans Frontières (MSF), and the Elizabeth Glaser Paediatric AIDS Foundation (EGPAF) amongst others. This allows funding agencies an opportunity to influence conditions for the engagement of PLHIV. While funding from partners include support for HIV medicines and equipment, it excludes hiring of staff (expert clients), yet human resources are fundamental for treatment expansion (Hanefeld and Musheke 2009). What is paradoxical is that implementing partners allocate funds to remunerate staff whilst another cadre in the same organisation is not compensated accordingly.

When officials from the Ministry of Health were sought for comment on this issue, government officials concurred it was an anomaly, but not a situation that required urgent rectification. One official told me, ‘As a ministry, we appreciate the work done by expert clients. We brought this issue to the attention of the Public Service. A decision was made that expert clients will be absorbed [into the public sector] in the next two fiscal years’. When I pressed him, asking for the rationale for waiting two years, he replied, ‘the ministry has core posts which are currently under donor funding that need to be prioritised, once that is done the expert clients will follow’ (Interview, April 2014). It was startling to learn that the Ministry of Health prioritised technical posts and disregard

experiential expertise when there was an acute personnel gap in the country, expert clients play a core role, and an urgent one yet the ministry's position reveal a disregard for experiential expertise.

Next, I was curious why funding partners did not assign a budget line to hire expert clients as full-time staff, like the rest of staff engaged in their organisations. One ministry official told me, 'our partners said that they could not afford to hire expert clients as full-time staff' (interview, December 2014). Against this backdrop, I wondered how there was a lack of funds to hire expert clients, when there were funds to hire the rest of the staff and to buy expensive equipment. During fieldwork in the clinics, I saw staff from funding partners arrive in lavish SUVs and many more littered throughout the city and countryside. Implementing partners procured expensive equipments (PIMA⁸, centrifuges⁹, mobile offices, office furniture, and computers) for the clinics, and hosted exorbitant workshops in fancy hotels. Furthermore, they flew in expensive expatriates for technical assistance to implement global policies to expand treatment. This sheer opulence belied the 'lack of funds' articulated earlier by the ministry officials. It appears implementing partners had money to spend on other expenses than expert clients.

To have greater insight on this matter, I researched how much it would cost to support the existing expert client programme. At the time of the study, an expert client received a stipend of E900/month (approximately 90 USD). Hypothetically, if there were 1,500 expert clients delivering HIV services in Swaziland, the budget would be around 135,000 USD per annum. A programme officer for ICAP or CHAI working in Swaziland earns a

⁸ A point-of-care machine used to measure CD4 count within blood specimen

⁹ a point-of-care machine used to separate fluids of different densities, in this case to get serum from blood specimen.

salary between 49–65,000 USD per annum, excluding benefits.¹⁰ This means one officer's annual salary can pay the stipend of 544 expert clients. In practical terms, the annual salaries of just three officers could pay the stipends for all of the expert clients in Swaziland. If expert clients were to be hired as full-time staff and their stipend doubled, the annual salaries of just six officers would cover that bill.

Needless to say, it is obvious that the reason for not engaging expert patients as staff could not entirely be attributed to a lack of money. In fact, spending patterns of the HIV response in Swaziland reveal that funding organization spent the majority of aid on human resources (NERCHA, 2010) but veiled as programme implementation cost which covers mainly technical assistance. The matter cannot be blamed entirely on funding partners either, because the 'volunteer' framework was established through many veins: the framing of the GIPA Principle at inception, the concerted call and desire for PLHIV to be involved in the response, the need to expand access to treatment despite acute human resource shortage and lack of State funds, and organisational weakness for PLHIV groups to demand accountability. Unfortunately, over the years, like tributaries flowing into the ocean, these different circumstances came together and positioned expert clients as volunteers. This paper describes how the shift occurred, -the willingness of expert clients to support the national response led to the manipulation of expert clients over the years. It is also a call for the government and donors to critically ruminate on what is at stake when a crucial programme relies on a cadre of volunteers.

¹⁰ <http://www.glassdoor.com/GD/Salary/International-Center-for-AIDS-Care-and-Treatment-Programs-South-Africa-Salaries>

Discussion

Ambiguities, Tension and Friction

After talking to different stakeholders involved in this twisted tale, it was clear that the hasty nature in which expert clients were engaged, in the midst of an AIDS emergency resulted in a lack of consensus on the scope of work and definition of the position of expert clients within the government structure. From the outset, different stakeholders defined and positioned expert clients differently. In such a situation, friction and ambiguities were unavoidable. Moreover, the design of public health programmes is largely influenced by a focus on the public good which always conflicts with the discourse on human rights (Chen, Evans and Cash 1999). An anthropological perspective is helpful to contrast the efficiency of the principles advanced by global proponents such as GIPA and investigate how these new strategies are experienced and affect existing norms and practises. This angle lobbies for a people-centred approach and brings a balance to the system-centred approach often used for treatment expansion.

From the donors' perspective, as set out in the task-shifting recommendations (WHO, 2007) expert clients were a readily available and cost-effective option to avert human resource shortage. The GIPA principle focused on fostering engagement of PLHIV through consultation on key policies and processes, advocating for treatment access and eliminating discrimination. Task shifting, on the other hand, articulated full-time involvement of PLHIV in service delivery to solve a human resources crisis. This one grey area potentially caused conflict and tension in the expert client programme.

One can conclude that formalization of GIPA was simply cosmetic and romanticised. The Ministry of Health rode on the emergency wave, using the king's call for all to be involved to elicit the help of PLHIV. While this helped to augment the HIV response in

many ways, as more human resource for health personnel expanded, the gains were skewed. PLHIV free labour was handed on a gold platter to HIV programmes.

The GIPA Principle 'Lost in Transition

Soon after the adoption of GIPA worldwide, became strongly involved in the HIV response through networks of PLHIV, and started to demand access to treatment, participate in decision-making to influence HIV policy (Epstein 1996). Their efforts paved the way for PLHIV to be engaged in addressing the HIV epidemic without fear of stigma. This was an early form of the GIPA principle, though the GIPA concept itself was not yet coined.

Different forms of AIDS activism began to take shape around the world. Nguyen's research (2010) describes PLHIV activism for HIV treatment in West Africa before ART was universally accessible. PLHIV used different strategies to access treatment and counter discrimination, including confessional technologies and volunteering with funding NGOs. Biehl (2004) shows the role of PLHIV in Brazil to successfully demand the government to provide ART. In South Africa, (Robins 2006) relates the crucial part played by the South African Treatment Access Campaign to increase access to ART. This paper demonstrates that there is another form of GIPA which is manifested in the increased involvement of PLHIV to provide institutionalized care, such as the role played by expert patients in the treatment expansion, yet is not articulated in the current GIPA principle.

The way expert clients are engaged has evolved differently in practise than articulated in the GIPA principle, and has resulted in injustices. When the GIPA Principle was developed in 1999 (Van Roey 1999), treatment was not yet available in the Global South and therefore the authors could not foresee how GIPA would evolve. If they did, they could have better defined the GIPA scope, distinguishing it from full-time institutionalised

health care positions. Needless to say, this omission could be resolved in practise. Instead implementing partners promote the engagement of expert clients as semi-formal volunteers in delivery of HIV care. Ferguson (1994) argues that African states are weak in challenging donor advances, and often do not take a stand against them, even for approaches they are well aware will not work. As such, funding agencies typically support project-based interventions (using temporary volunteers) rather than providing structural funding (permanent staff positions). With little activism in Swaziland to push for a paradigm change, the prejudices for PLHIV engagement and the valuable experiential expertise that PLHIV render in the response will continue to be under-valued.

Care provided by laypersons continues to be undermined and this conceals the overall cost of treatment as expert clients are positioned as a cheap labour and budgeted as such. AIDS programmes are led by personnel with medical training, and this may contribute to a lack of appreciation for non-medical expertise. Hence, institutionalizing expert clients could validate the power expert clients have. Also, there may also be tensions between medical workers and non-medically trained workers, as found by Kyakuwa, Hardon and Goldstein (2012) in Uganda that expert clients became more experienced than nurses were on ART issues. Furthermore, expert clients became adepts in taking treatment and counselling PLHIV to resolve challenges patients encountered as a result of their infection. This means experiential expertise of PLHIV is becoming valuable especially in poor resource setting that suffer an acute lack of human resources to scale up treatment. Hence it is pivotal to consider the position of expert clients within the health system and institutionalize them in order to bridge the existing gap in human resources for health. At a global level, there is need to review the GIPA principle in the context of rapid treatment expansion and capture the new forms of GIPA taking place within institutionalized care. Therefore, the current framing of GIPA under a volunteerism framework needs an evaluation, lest funding

agencies risk being labelled what Heggenhougen (2000) termed ‘commerciogenic capitalism’, an out-of-control economic force that promotes inequality akin to capitalism.

Conclusion

Undoubtedly, GIPA supported the expansion of the ART programme in Swaziland, as it did in other poor-resourced countries (Kielman and Cataldo 2010; Zachariah et al. 2009; Tenthani et al. 2012). This is laudable: it means global initiatives have succeeded in aiding countries to expand treatment. However, these ‘travelling policies and strategies’ (Hardon and Dilger 2011) have had unintended consequences (Merton 1936), turning an initially willing group of volunteers into a workforce that has suffered many prejudices. PLHIV acted as responsible citizens (Robins 2006), heeding the king’s battle-cry and the global call against AIDS, to the eventual detriment of their own well-being. This organisational weakness persists: current PLHIV issues beyond access and discrimination have no fora to address them. This is not the case in Swaziland only; an advocacy agenda addressing prejudices around GIPA and organizational weaknesses for PLHIV networks is missing in the call for action by PLHIV representatives at the global and regional levels.

If an aid-funded programme requires the services of PLHIV, the onus is on government, along with civil society as watchdogs. By not setting standards for PLHIV involvement, the government appears to condone the volunteer framework used by funding NGOs to elicit low cost labour. This passivity allows ills to be normalised. Precedence to save lives and using international instruments to implement global initiatives is encouraged, however should not supplant critical national processes. Donors’ suggestion to bypass the national policy process was supposed to be an interim measure, was established as a norm such as using TWG rather than the painstaking process of developing a policy. Strengthening the health system needs to take precedence than to implement ‘projects’ with short timeframes

which require minimal investment to long-term structural improvements of the public health system.