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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 2

Methodology

Study design

The premise of this ethnographic study was that people divulge details about their social life and behaviour according to the level of familiarity and trust established between the researcher and the interlocutor (Price and Hawkins, 2002, p. 1328). I conducted a review of relevant policy documents and international guidelines that have steered the HIV response at the local and international level. I also enrolled into an HIV testing and counselling (HTC) course to have an embodied experience as a health worker at the frontlines of HIV services provision. To gain insight into patient experiences, I conducted in-depth interviews and focus group discussions as well as holding informal conversations to triangulate findings.

Situational analysis

Before the study commenced, I conducted a six-week-long situational analysis of the ART programme in Swaziland. The situational analysis had three objectives: 1) to understand the scope of the ART programme; 2) to comprehend barriers to access, perspectives of service providers, and research questions that the study could focus on; and 3) to learn the perspective of the Ministry of Health regarding the MaxART programme, which aimed to expand treatment and to use ART as prevention. I was interested in the studying the health system's readiness to achieve MaxART objectives and the challenges of using ART as prevention. This analysis involved obtaining all data and reports of the ART programme in Swaziland, including published research and grey literature. I reviewed these materials, as well as studies and HIV-related policy, guidelines, and protocols used to scale up treatment in the country. In addition, I visited four health centres that provided ART initiation services to observe processes and to interview health workers that were on the frontlines of ART provision. I visited a community clinic, a health centre, and a hospital to observe the HIV continuum of care and to interview health workers.

Data was collected from five clinics in total wherein in three of them I was an HIV counselling trainee for 6 weeks. The training was divided into two: lecture training for 2 weeks on the theory of HIV counselling and three weeks of attachment in a clinic and provide HIV testing and counselling services. The two more clinics were research sites for in-depth ethnographic research. I became a professional counsellor through the training and it qualified me to be part of the counselling team in the two clinics that became my research sites and hence permitted to collect observational data during counselling sessions. Data was also gathered through in-depth-interviews with PLHIV who were eligible for but did not initiate ART in 2011 when MaxART project was introduced.

Participant observation

During the HIV counselling course, when I was attached as an intern, I observed clinical processes involved in the delivery of HIV care, had conversations with health workers, and provided counselling to 84 PLHIV. Attending the counselling course allowed me to gain first-hand experience in providing HIV services as a health worker, to compare counselling services in practice with counselling as taught in the classroom, and to gain insight into the factors that led counsellors to circumvent guidelines. During the practicum period as a counsellor trainee, I provided pre- and post-test counselling and adherence counselling to different PLHIV patients. Being positioned within the health system allowed me to have a vantage point on issues that caused patient drop-outs as well as minimal linkage in the continuum of care. Being attached in the counselling department gave me an opportunity to observe clients at all the different service points in the care continuum because counselling was the gateway for all services: before testing, to prepare PLHIV for ART initiation, and in making corrective action for non-adhering patients.

I conducted observations at the two clinics that were research sites and I observed 245 HIV

counselling sessions and over a period of 20 months. During these observations, I took field notes on the information that was given to patients immediately after diagnosis, the manner in which the information was given to newly diagnosed people, the interaction between the clinician and PLHIV in the counselling room, and specifically I was interested on the dynamics and quality of communication with clients who defaulted their scheduled clinic appointments. Additionally, I participated in daily duties of the counsellors: help to track patients, sorting patient files, filling registers, and booking and re-booking of patients. In a nutshell, the ethnographic immersion in the two research clinics allowed me to have a healthcare provider perspective within routine clinical settings that provide HIV services.

The observations went beyond the counselling room to the entire ART department in the two clinics. I spent two months on full time in each of clinic I observed the ART related clinical operations: in the laboratory, consultation rooms, the ART nurse's station, and the dispensary where I was oftentimes requested to pack medicines. After the two months period for observation in each clinic was finished I returned periodically to follow up with study respondents until the end of the research period. I also made direct observations of clinic logistics: how queues were managed, the mechanism for tracking defaulters, and general record keeping of clinical data. All documentation was mined to give an overview of patient histories and demographics. Many numerous informal conversations were held with ART staff; nurses, expert clients, phlebotomist and the clinic orderlies. I also partook in many conversations in formal gatherings such as the MaxART biennial face-face meetings and overheard some during informal contexts with peer clinic staff during lunch or tea breaks, or during rides home.

In-depth interviews

Research subjects for in-depth interviews were purposively selected from two sources: those

picked during the counselling sit-in sessions and those reported by counsellors as defaulters. HIV-positive clients earmarked for ART initiation were routinely scheduled for a series of counselling appointments, should a client fail to show up for an appointment such a person was put in a pile of defaulter file. From the pile, I focused only on those who were scheduled to start ART in 2011 when the MaxART project began. Routinely, counsellors tracked defaulters through calling to get the reason for the missed appointment and to re-book them. When clients returned to the clinic, I invited them to participate in the study and asked for consent after explaining the phenomenon under enquiry.

The selection of respondents zoomed only to clients who failed to return to the clinic for scheduled appointments, and those who verbally expressed their unwillingness to take antiretroviral medications as their reason for defaulting. Seventy one of 93 clients who met the selection criterion agreed to be interviewed and 104 life-course interviews with this group were conducted. The 22 clients could not be interviewed; several refused and others proved impossible to track.

In upholding confidentiality, each participant was interviewed a place and time convenient to them. SiSwati, the native language was used during the interviews. The interviews started off as a natural conversation about their overall experiences at the clinic and as the conversation evolved I specifically probed the reasons they had not returned for scheduled appointments. Majority of interviews lasted half an hour to 2 hours. They were recorded and transcribed verbatim and translated into English.

Focus group discussions

I conducted focus group discussions in eight clinics with 21 expert clients, who were the total staff all expert clients working in those clinics. These focus groups were organized to gather and corroborate information on the issues discussed during one-on-one interviews.

The issues discussed included: the scope of duties performed by expert clients, challenges encountered in the line of duty, and how expert clients navigated around them. The FGD ranged between one and a half hours to two hours in duration. Expert clients that were interviewed individually were not selected for the FGD.

Data handling and analysis

As the study approach was ethnographic, the sample was small. Through triangulation I sought internal validity. Generalizability was not the focus of the study per se, instead it was an in-depth examination of the strategies and processes adopted, and how system-related factors affected whether patients stayed in the continuum of care.

Data was captured through note taking, audio recording, and photography; interviews and focus group discussions were transcribed verbatim and translated to English. Ethical consent was obtained in writing from all participants for in-depth interviews for the first interviews; for subsequent interviews consent was given verbally.

Ethical approval

Ethical approval for the research was granted by the National Health Research Review Board in Swaziland and the ethics board of the University of Amsterdam. In addition, written permission was granted by the director of the AIDS programme in Swaziland to enter the clinic, access patient files, and conduct observations during counselling sit-ins. Patients signed a consent form before interviews were done, whilst health workers consented verbally since they came from the same clinics where the study was done.

Study setting

The three sites where I had my practicum were randomly allocated by the lecturer and the two clinics that became sites for the ethnographic research were selected. Two criteria were

used to select the sites: (a) it must be a MaxART intervention site, meaning a clinic where necessary point of care ART technologies were available and services accessible to meet demand of services in order to sufficiently enhance uptake of treatment (b) the clinic management have shown high motivation and commitment in good ART outcomes. This means only MaxART clinics were selected as research sites as periphery communities were already involved in rigorous community mobilization to create demand for HIV services, point of care services available and the clinics with trained staff to accelerate efforts to enrol PLHIV to care. Finally, sites with high ART patient volume in both rural and urban locales were desirable to be part of the sample to possibly enrich varied understanding for non-uptake and limited retention to HIV of people in care rural and urban areas. Clinics that had good and poor performances were excluded as study sites to eliminate best and worst scenarios that might not be ideals and representative of average facilities.

Clinic A

Clinic A is a peri-urban community clinic at the outskirts of the capital city, Mbabane. It has a catchment population of 16,162 and servicing a population of 3, 0890 (Central Statistics Office, 2007). The majority of the population lives within a 5 to 8km radius of the clinic. It is a small but very busy clinic as it attracts people from the city who avoid the national hospital and other private and semi-private clinics in the periphery of the city. The patient volume is high and it is amongst the ten busiest clinics in the country.

As a community clinic, it is run by a clinic committee comprised of representatives from the clinic and community. The committee oversees the affairs of the clinic and ensures the welfare of the staff. The clinic works closely with community health volunteers called rural health motivators (RHM). RHM work with expert clients to trace defaulters and link them back to care, and this effort is done through support from World Vision, an international

NGO. Clinic A had seven nurses, five expert clients (three for general ART patients and two for prevention of mother-to-child transmission of HIV patients), one officer responsible for TB screening, a phlebotomist, an orderly, and a dispenser of medications. A doctor from the Ministry of Health came for to initiate people on ART on Fridays each fortnight, whilst one of the implementing partners provided mentoring to this ART clinic each week.

The ART clinic is stand-alone, prefabricated structure on the premises of the main clinic. It has three consultation rooms. The first is a pre-test counselling room where patients are counselled before taking an HIV test, and where newly diagnosed people are enrolled to care. The second is for adherence counselling for patients, where pill counts are conducted and files of those on ART are kept. The last consultation room is where the ART nurse does physical assessment of patients, and staging and refilling of drugs. There is a small laboratory within the main clinic where CD4 analyser is kept. Also kept in the same room is a centrifuge, a fridge, and basic laboratory accessories for drawing specimens. Results are received within 20 minutes. CD4 counts are measured twice a week; if patients come on any day outside of these, they are asked to come back on the proper days. Also, specimens for liver function tests (chemistry profiles) are collected there and sent to the National Referral Laboratory (NRL). The turnaround time for chemistry profiles from the NRL is two weeks.

Clinic B

Clinic B is a community clinic, located in the Lubombo region, approximately 200km away from the capital city. The catchment population of the clinic is 10,001. It is in a rural community, dotted with homesteads and fields and livestock wandering about. The community has stick-and-mud houses as well as brick-and-mortar houses with electricity. There is a main road with tarmac less than 1km away, connecting the sugar belt, Big Bend, and Simunye, including Siteki, the capital of the Lubombo region.

Many of its characteristics are similar to Clinic A in terms of staff composition and arrangement of services. Counselling services are offered in one of the rooms in the main clinic. During the fieldwork period, there were two counsellors in one room, one focusing on pre-ART patients whilst the other focused on ART patients. The prefabricated structure was used as a mini laboratory.

Thesis outline

The thesis investigates the global health HIV policies used for scaling up HIV treatment that were adopted by the Swazi public health system. It tells a story of global policies, travelling from the global to the local (Hardon & Dilger, 2011; Adams & Biehl, 2015), and how the adopted processes and policies were manifested in the localities where they were adopted. It examines how specific policies and processes were adopted and what changes occurred to health care delivery as a result of the policies. Specifically, it looks at the shifts in health care delivery at the micro-level and explains how unintended consequences occurred as policies metamorphosed from intended objectives to practice, and how those who encountered the policies navigated the unintended circumstances that resulted.

The thesis consists of four chapters, each of which is an article submitted for publication. The first article, “‘Lost to follow up’: Rethinking delayed and interrupted HIV treatment among married Swazi women’ was accepted for publication in August 2016 by *Health Policy and Planning*, and published in October 2016. As I investigated the reasons for patients’ failure to link to HIV care and the inability of the health care system to achieve optimal retention, it was not long before it was clear that married women and women in long-term relationships seemed to struggle with returning for scheduled appointments. Intrigued, I wanted to get more insight into why these women were more susceptible to missing scheduled appointments and dropping out of care prematurely. I found that women in long-term relationships carefully make decisions and prioritize honour in marriage and filial duty before their own health needs. Upholding honour means that women have to live within the expectations of their spouses (and largely their kin) even if it means delaying treatment. Treatment could not occur without the express blessing of the spouse, which meant that women had to engage in a protracted negotiation process with their spouses.

While MaxART attributed low uptake of treatment to access barriers, my study shows that no matter how close the services were, married women still missed their appointments. This article illuminates the gendered and cultural nature of treatment uptake that public health practitioners often exclude in programming, and shows that availability of drugs, access to services, and equipment alone will not spur the desired uptake of ART.

The second article is titled ‘Task shifting or shifting care practices? The impact of task shifting on patients’ experiences and health care arrangements in Swaziland’. It was accepted in *BMC Health Services Research* in December 2016 and published in January 2017. It focuses on task shifting as one of the global strategies aiming for treatment expansion, and looks at the consequences of this implementation science on health care settings. I was drawn to this topic because task shifting was recommended as an effective strategy for treatment expansion to resolve key challenges faced by the public health system, namely improving patients’ experiences and resolving the shortage of health personnel in a context of increased demands for ART services. However, during 25 months of ethnographic research in clinics, I observed manifold undesirable consequences of task shifting on the public health system and on patients. What was fascinating to me was that there was little said by global health proponents, programmers, or researchers about the other effects of task shifting; they focused only on the positive aspects. This selective representation of task shifting’s efficacy was intriguing to me because my observations showed that the practice left undesirable imprints on the health care system.

Furthermore, bottlenecks in treatment expansion were normatively conceived as part of the health system that required a structural and logistical fix. Patients’ therapeutic experiences often remain at the periphery during the planning stage and were only considered within the context of monitoring and evaluation audits once programmes were up and running. My

research found that some patients did not link to care or drop out before ART initiation because of the protracted and unfriendly processes that were introduced by task shifting. Access to care had become rigid and deterred patients from pursuing biomedical care. The quest to show evidence of the efficacy of implementation science shadowed practical and irrefutable evidence provided by patients.

‘The GIPA concept “lost in transition”: The case of expert clients in Swaziland’ is the third article included in the thesis, and it was accepted by *Anthropology in Action* for publication in 2017. This article examines how following treatment expansion principles can result in negative consequences. Volunteerism is the backbone to expand health worker shortages in resource-limited settings such as Swaziland. I wondered why the treatment expansion agenda, as driven by donors and implementing partners, relied heavily on volunteers, how this trend was established, and why donors shied away from investing in the health care system. Rather than strengthening the health care system for sustainability purposes they preferred to ‘projectify’ their interventions, funding projects rather than the system itself (Whyte, 2014). The article 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 in treatment expansion coupled with donors’ promotion of the GIPA principle together resulted in PLHIV serving as low-cost workers. Health workers work under immense pressure to reach donor targets, assuming increasing tasks brought by treatment expansion, but without incentives they end up ‘burnt out’. This resulted in unpleasant experiences for patients, who complained of disciplinary instead of empowering approaches to care, which became a deterrent to PLHIV seeking care.

The last article is entitled ‘Relationship dynamics amongst expert clients in healthcare settings in Swaziland: Creating, sustaining, and severing bonds’ was submitted to

Anthropology and Medicine in January 2016 and is still under review. In order to meet the demands of treatment expansion and more specifically to close the personnel gap, PLHIV under GIPA were introduced as expert clients into biomedical spaces (clinics). Expert clients started by providing counselling services, but their duties grew from year to year, as they took on a range of tasks previously performed by nurses. I was amazed by expert clients' diligence and resolve to provide care with passion regardless of their swelling workload, as they worked far more hours than what volunteers are expected to contribute in a day. They not only had to manage the workload and perform their duties satisfactorily, or lose their contract, but also, they had to deal with tensions and conflict among themselves and with nurses. I was interested in knowing how expert clients navigate the conflicts and tensions they encounter in such highly contested work environments, and specifically how they cope with the challenges that result from their engagement as volunteers. Treatment expansion had taken such pre-eminence within the clinics that conventional structures to manage such conflicts fell under the radar. Different strategies were adopted by expert clients to cope, including through bonding with each other and creating alliances to support each other when conflict arose. However, this was not always the case as there was sometimes conflict among them. Some expert clients became the nurses' puppets in return for favours and as such were considered sell-outs and usually in conflict with the rest. Conflict amongst expert clients was also caused by the fact that different partners paid different stipend amounts.

This dynamic was peculiar to witness because research (Biehl, 2004; Robins, 2006; Epstein 1996) had portrayed PLHIV as a group that esteemed solidarity and used it to make strides and achieve many successes, including ensuring universal access to HIV treatment and involvement of PLHIV in health policy at the global level (Morolake, 2009). But the impact of global health strategies such as task shifting and GIPA does not end at the confines of the

clinic to augment treatment coverage, avert acute human resources shortages, and improve patient experiences; it also has larger social ramifications, configuring new practices and shaping norms and meanings. Beyond the demonstrated benefits as travelling global HIV policies and strategies are implemented, there is a caveat: they put immense pressure on health care settings and often there is no time left to invest into health workers' welfare.

The research findings indicate that another reason for delayed uptake or non-uptake of HIV treatment was that patients' use of medical information received from clinicians was influenced by a myriad of reasons beyond just access to services. PLHIV had to make sense of the information and would apply it within their social space only if doing so would not jeopardize existing relationships, and more specifically would not deprive them of honour. If applying medical information would put honour at stake, that medical advice would not be followed. Access to care was found to be a tactical process and oftentimes the decision to pursue a particular therapy was a decision made by a group of people, not an individual. Though sometimes PLHIV would miss appointments, quality and timely access to care when hurdles were successfully overcome was a big determining factor to stay in care.

As treatment was expanded, new procedures were introduced that tended to make access to ART a very protracted process. Yet the majority of people who arrived at the clinic were already symptomatic and could not wait to complete the long process before treatment could be started. PLHIV expected to find quality care; if they didn't, it deterred them from staying in care. Early initiation to such levels that HIV is not transmittable requires not only a logistical fix but a cocktail of interventions, both socially sensitive programming and quality services in the health system, so that those individuals willing to start treatment are not deterred by an unfriendly therapeutic experience. Furthermore, travelling policies affect the landscape of care, shape patient therapeutic experiences, and alter long-established norms

and practices between patient and practitioner. Public health leaders should be cautious about standardizing metrics and generalizing the effectiveness of implementation science as these may vary due to distinct circumstances in resource-poor societies that may lead to different outcomes of treatment expansion than anticipated.