

Between the Clinic and the Community: Temporality and Patterns of ART Adherence in the Western Cape Province, South Africa¹

Larkan F

Centre for Global Health, Trinity College Dublin, Ireland

Email: larkanf@tcd.ie

van Wyk B

School of Public Health, University of the Western Cape, South Africa

Stevens P

Department of Anthropology & Sociology, University of the Western Cape, South Africa

and

Saris A.J.

Department of Anthropology, Maynooth University, Kildare, Ireland (corresponding author)

Abstract:

In an ethnographic study conducted over thirty months in South Africa's Western Cape Province ending in 2012, we explored ART adherence amongst almost 200 patients attending three clinics. This setting contained significant political, structural, economic and socio-cultural barriers to the uptake of, and adherence to, treatment. Such barriers certainly impacted patient drug use and the labelling of clients as 'adherent' or 'non-adherent'. Yet, as our fieldwork developed, it became apparent that these labels also bore little relationship to the amount and regularity of drug consumption outside the clinic. Indeed, the people that we knew moved through these labels in ways that could not simply be explained by brute socio-economic circumstances, poor understanding of the functions of the drugs, or varying levels of family and community support, which themselves often changed over time. This paper presents four on-going 'patterns of adherence', which are clearly discernible in the communities in which we worked. Each pattern is demonstrated through the life of an 'index patient' whose case is seen to be representative of the range of experiences and practices observed under the terms 'adherent' and 'non-adherent'. We argue that such terms are deeply contextual and, crucially, temporally situated. The complex intertwining of political, economic, socio-cultural, gender, and biological factors that constitute the lives of participants exists in time and we call for a focus on evolving lives in relationship to changing health systems that can follow (and respond to) such developments to better deliver both information and services.

Key words: ART adherence, community, health systems, socio-cultural barriers drug consumption

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Résumé

Dans une étude ethnographique menée sur trente mois dans la province du Cap occidental en Afrique du Sud se terminant en 2012, nous avons exploré ART adhésion parmi près de 200 patients fréquentant trois cliniques. Ce paramètre contient obstacles politiques, structurels, économiques et socio-culturels importants pour l'absorption et l'adhésion au traitement. Ces obstacles certainement touchés usage de drogues patient et l'étiquetage des clients comme «adhérent» ou «non-adhérent. Pourtant, comme notre travail de terrain développé, il est devenu évident que ces étiquettes portaient aussi peu de rapport avec la quantité et la régularité de la consommation de drogue en dehors de la clinique. En effet, les personnes que nous connaissions déplacé à travers ces étiquettes d'une manière qui ne pouvait pas simplement être expliquées par les circonstances socio-économiques brute, une mauvaise compréhension des fonctions de la drogue, ou des niveaux variables de la famille et le soutien de la communauté, qui se souvent changé au fil du temps. Ce document présente quatre en cours "motifs d'adhésion", qui sont clairement visibles dans les communautés dans lesquelles nous avons travaillé. Chaque modèle est démontré à travers la vie d'un patient de l'indice 'dont le cas est vu pour être représentatifs de la diversité des expériences et des pratiques observées en vertu de l'adhérent »et de« non-adhérent. Nous soutenons que ces termes sont profondément contextuelle et, surtout, située temporellement. L'enchevêtrement complexe de politique économique socio-culturelle, de genre, et les facteurs biologiques qui constituent la vie des participants existe dans le temps et nous appellent à une mise au point sur l'évolution de la vie dans la relation à l'évolution des systèmes de santé qui peuvent suivre (et de répondre aux) tels développements pour mieux offrir à la fois des informations et des services.

Mots clés: ART adhésion, la communauté, les systèmes de santé, les barrières socio-culturelles la consommation de drogues

Introduction

This paper traces actual antiretroviral (ARV) usage in the lives of people living with HIV in situations of often-extreme structural violence, alongside their relationships to the medico-bureaucratic labels that form the portal to their life-saving medication. We centre our observations and analysis on the moving interface between clients and clinics, a membrane where multiple agencies and logics – in the shanty, in the clinic, and indeed globally – intersect over time, but which are usually tracked in a series of snap-shots, reducing them to seemingly clear categories of 'adherent', 'non-adherent' and 'lost to follow-up'. Such labels are not trivial, as they position individuals in ways that impact everything from their continuation on these drugs to understanding the effectiveness of treatment at regional, national, and global levels. At the same time, these labels are not simple: they shift over time and with respect to scales of analysis. Crucially, the same label can also cover very different patterns of actual drugs usage, while similar patterns of partial usage are sometimes discriminated through

different labels. We conclude that this complexity requires much closer ethnographic and theoretical attention and we suggest that the interface between the clinic and community should be the focus of this attention.

We start by locating some of the larger discussions of adherence in powerful discourses that provide funding for programmes and survey their results. In doing so, we chart some of the complexities of surveillance and reporting categories upon which so many lives ride. We then chart in our own work some of the ways that distinct lines are drawn between very similar patterns of the use of these medications while at other times very different patterns of use appear in the same category. At the same time, we reveal surprising levels of movement between seemingly neat categorizations that eventually code (in clean statistical tables projected in well-appointed conference rooms) the impact that these drugs are having. It is only when snap-shots are put back into social motion that can we see how important time is in understanding this complex social-medical situation. We offer this analysis not as a critique of global antiretroviral treatment (ART) policy, but as an encouragement for ethnographers to engage more directly the temporal aspect of ART, especially as reinvigorated focus on health systems is emerging as a significant issue in Public Health and Global Health.

Background

While the history of the struggle to gain popular access to antiretroviral treatment (ART) in the Republic of South Africa is well known in the literature, it still seems useful to review some of the highlights of this success here. After sustained pressure from civil society organizations and the breaking of the Northern-held patent on antiretroviral (ARV) medication in 2001, the South African cabinet committed the government in 2003 to a public sector antiretroviral treatment ART rollout. By the end of 2013, over 2.5 million people were receiving ART (SA Dept. of Health, 2013-2014), and South Africa is now widely acknowledged to have the largest and best-established antiretroviral treatment programme in the world.

Since the 2003 rollout of ARV medication in South Africa, HIV has for many people changed from being a fatal disease to becoming a manageable chronic illness (Mitchell & Linsk, 2004). However, the successful management of this chronic illness is strongly dependent on the patient's adherence to ARVs. An optimal adherence rate of 80-95% is required if medication is to be successful and the desired outcome – slowing the progression of the illness and decreasing morbidity and mortality rates from secondary infections – is to be achieved (Garcia & Cote, 2003; Battaglioli-DeNero, 2007; Shah, 2007; Ingersoll & Cohen, 2008). Sub-optimal adherence to antiretroviral treatment can cause treatment failure and, potentially, drug resistance, so we observe a wide variety of interventions in Public Health to assure as full adherence as possible in a population using ART.

Western Cape Province, in partnership with *Médicins Sans Frontières*, launched the first highly active antiretroviral treatment (HAART) program in May 2001 in defiance of national policy (Naimak, 2006). By March 2003 the province announced that all HIV-positive pregnant women could access the antiretroviral drug, Nevirapine, at their nearest clinic. The current HIV prevalence in the province is 18.2% (approx. 1,055,600 people) (<http://www.avert.org/south-africa-hiv-aids-statistics.htm>) with a reported 156,703 patients in the province receiving ART at the end of 2013 (Western Cape DoH 2014: 212).

ART suppresses the virus and reduces viral replication to undetectable levels, turning a disease that had once been rightly feared as a death sentence into a chronic condition, potentially granting decades of life. However, in order for the treatment to be effective, a high rate of treatment adherence is required. The consequences of non-adherence, at the individual level, are a faster progression to full-blown AIDS, a much more expensive treatment regimen as other drugs are prescribed to stem the rising viral load, and potentially treatment failure and death. The Public Health fear is that incomplete adherence on a large scale could potentially produce very resistant strains of HIV, reversing the remarkable success story in the control of this plague in the last twenty-five years. Thus, the massification of ART resulted in increasing research on how to get people to become and remain 'adherent', and programme effectiveness is judged by the proportion of people who inhabit this category.

Adherence as an Optic and a Goal in Global and Public Health

From the innovation of HAART in the early 1990s, *adherence* emerged as a key health and policy issue. Patients needed to take their medication exactly as prescribed, while also following the necessary dietary restrictions. The 2003 World Health Organisation report - *Adherence to Long-term Therapies: Evidence for Action* states that adherence is not only about taking medication properly, but also about behaviour, including arriving for appointments at the healthcare facility. Thus adherence is defined as 'the extent to which a person's behaviour - taking medication, following a proper diet, and/or executing lifestyle changes - corresponds with agreed recommendations from a health care provider' (2003: 17). Therefore, adherence is also closely linked to the issue of accessing medication and using it properly, even if it is not completely co-terminus with drug use (Reif et al, 2005). Indeed, for many people in need of ART, the process of accessing health facilities still serves as a great barrier to adherence (Reif et al., 2005; Tuller et al., 2010).

After the breaking of the Northern patent on ART and the massification of this therapy, adherence emerged as a global concern, as funders and Global Health decision-makers searched for ways to measure impact and understand unmet needs. This added

another definitional layer around “adherence”. For example, “full coverage” is defined by the WHO as getting ART to 80% of those in need in a population. The data from four-year follow-up studies throughout the world, however, shows that adherence ‘trajectories’ tend to track downwards over time, with adherence rates after four years falling to around 70% at the end of most of these studies (UNAIDS, 2012). In other words, in most resource-constrained settings, almost half of the people who might imagine themselves to have access to this form of therapeutic citizenship still do not (or have fallen out of this status) after only four years in populations deemed ‘adherent’.

These disparities present disquieting theoretical challenges, as scholars try to tease out ideas of discipline, medical necessity, and various understandings of agency in radically different settings, with literally life-and-death stakes in play. In this debate “adherence” jostles with seeming synonyms, such as “compliance” to mark out different understandings of how the life-world of patients relates to ART. Historically, some studies argued that adherence is the same as compliance (Shah, 2007; Ingersoll & Cohen, 2008), while others (Kaijee & Beardsley, 1992; WHO 2013) argue that the two are entirely different concepts, with ‘adherence’ being the more appropriate term. Kaijee & Beardsley (1992), on the other hand, point to the medically defined concept of ‘compliance’ as uni-dimensional and as a failure to recognize the patient’s agency. WHO (2013) argues that while the relationship between the healthcare provider and the patient must be a partnership during which the treatment process is discussed, ‘compliance’ implies that patients are passive participants in their treatment process, and does not acknowledge the necessity of such a partnership.

Maskovsky (2005) also challenges this emphasis on ‘adherence’ rather than ‘compliance’, which he argues ‘places the burden – and much of the blame – for the failure of HIV drugs on the people who take them’ (see also Mattes 2015). As Crespo-Fierro (1997) notes, the reasons for non-adherence are generally multifaceted. Factors that negatively impact on adherence to ART are generally categorised into four groups - disease-related, patient-related, provider-related and treatment-related (WHO, 2003; Hardon, et al, 2007; Bardel et al, 2007; Spire et al, 2002; Hubbard, 2006). Linguistic and communication factors, such as those highlighted by Penn et al (2011) have also been pointed to as issues in adherence. There is also the significant issue of the political economics of access (Nattrass, 2008) or the political decision-making processes that place voter interests ahead of patient need (Bruera 2006) in the distribution of scarce resources.

We also have detailed ethnographies of people with HIV trying to access treatment, and indeed health, in extremely trying circumstances (see especially Biehl 2007, Zigon 2010). In such work, however, the clinic is constructed as a semi-opaque bureaucratic structure, and we are unclear how the messy complexities we see in the ethnography are structured into the reporting categories that inform donors and international health organizations of the effectiveness of their interventions, while the ethnography

beautifully (if tragically) documents often very partial adherence. In other words, the question is not just the ‘limits of surveillance’ in Biehl’s apt phrasing (2007:179-180), but also understanding the specific means through which surveillance as such is enacted in particular times and places in relationship to actual patterns of drug use.

Factors Explaining Non-Adherence

Disease-related factors

Adherence to medication is poor when the illness is asymptomatic and chronic. Advanced illness as well as exposure to painful symptoms and side effects may result in a greater likelihood of the patient following the treatment as prescribed (Abel & Painter 2003, Battaglioli-DeNero 2007, Gay et al 2010). In one American study, disease severity was identified as playing a key role in adherence, as patients who have experienced complications from the disease may believe that they are at greater risk of their disease getting worse if they do not adhere to ARVs (Gao et al, 2002). On the other hand rumours of bad side-effects discourage attendance among some (Grant et al 2008) while in the South African context, early political equivocation regarding lay and untested HIV remedies led many to explore these options instead of, or alongside, their ART treatment (Mills 2008).

Patient-related factors

Acceptance and disclosure of the disease facilitates support from family and friends, which can impact positively on adherence (Battaglioli-DeNero 2007). Culture, religion, health beliefs, health practice and motivation can have both a negative and a positive impact (Ezekiel et al. 2009, also Russell and Seeley 2009). Kalichman et al (2005) identified the need to develop the adherence skills of patients, and provide devices or strategies to help adherence. Failure to fill prescriptions, missing and forgetting doses (Katzenstein, 1997), incorrect dosing and self-regulating the regimen to manage side effects are additional negative factors (WHO, 2003; Hardon et al, 2007; Nam et al, 2008). Other factors identified, which contribute to poor adherence, were stigma, hunger, transport cost (accessing healthcare facilities) and substance abuse, including alcohol consumption (Reif et al, 2005; Conen et al, 2009; Hardon et al, 2007).

Provider-related factors

In attempting to address adherence, studies often focus on patient-related adherence factors rather than provider-related adherence factors. With the increased prevalence of HIV, healthcare systems have become overworked and understaffed. This has resulted in a lack of counselling expertise and time to counsel patients properly. Linguistic barriers may impede communication of treatment regimen; therefore language and literacy issues, particularly in multilingual sites such as Western Cape, are often seen to impede the provision of equitable care (Deumert 2010, Penn et al 2011). Where there is ART regimen complexity providers need to tailor regimens to individual lifestyles (Battagliolo-DeNero 2007). An overestimation of adherence readiness and willingness may result in inaccurate adherence predictions, as patients may not fully comprehend their regimens (Ingersoll & Cohen, 2008).

The quality of healthcare provider (HCP) communication with the patient, is an important determinant of adherence (Abel & Painter 2003, Hargie 1999, WHO 2003); and thus of the actual therapeutic process and behaviour. Tugenberg et al. (2006) found that patients' relationships with HCPs played an important role in patients' non-adherence and the disclosure thereof. Participants in this Massachusetts-based study confirmed that the emphasis and 'insistence' on adherence sometimes had the opposite effect, and that non-adherence is often not disclosed due to concerns of being seen as a bad patient or to avoid being reprimanded. Lack of disclosure of non-adherence was also a way to avoid 'disappointing' the HCP (Tugenberg et al, 2006).

Treatment-related factors

Poor adherence can be due to the complexity of the regimen, dosing times and the number or variety of pills the patient has to take (Battagliolo-DeNero, 2007; Gallant, 2002; Ingersoll & Cohen, 2008). Generally, if a dosing schedule that coincides with daily routine has not been planned and implemented, difficulty in adherence to treatment is likely to occur.

Thus, adherence has a dual quality in the literature; that is, it exists as both a state and a process (Gray 2006). Patients' lives can display, at different times and in different circumstances 'erratic non-adherence', 'unwitting non-adherence' and 'intelligent non-adherence' (Donovan & Blake 1992), but at any moment in time there are a very limited number of ways to view and tabulate these patterns. To this extent, it seems that a much more serious engagement is required with the relationship between temporality, actual use of medication, and the clinical gaze.

Methodology

We worked over a period of 30 months from 2009, in the West Coast region of Western Cape Province (Saris et al, 2012). The three ART clinics that form part of this study have a catchment area of approximately 450km, with a population of close to 500,000. In June 2009 those three clinics combined had 1,212 people (1126 adults and 86 children) attending for antiretroviral treatment (Western Cape DoH, personal correspondence, June 2009). Province-wide during 2009 approximately 2,500 people were being initiated onto antiretroviral therapy per month, and it was anticipated that this number would need to be maintained for 3-5 years (Western Cape DoH Annual Performance Plan 2011/2012).

In addition to the three ART clinics, our research site included ten referring primary health care clinics (PHCs), five Non Governmental Organisations (NGOs) who provide outreach services, and the homes of numerous people on ART. Outreach staff were instrumental in introducing us to HIV-positive participants who were not attending the clinics and therefore were deemed 'non-adherent', so we had regular access to some patients that the clinics themselves wanted to bring closer. In other words, our team had a presence in all of the formal clinical settings people accessing ART could attend as well as having a presence in their homes and local communities. Thus, we were able to follow not just people, but also information and objects (especially pharmaceuticals), repeatedly across the interface between the clinic and the community.

Patient participants were recruited through both convenience and purposive sampling at ART clinics or through outreach workers in the community. In addition to patients, a total of 36 health worker participants (doctors, nurses, pharmacists, support staff, outreach workers, etc.) were purposively selected on the basis of their stakeholder status and their ongoing interaction with patients. The principles of written informed consent were applied in all cases.

Ethical approval was obtained from the Western Cape Provincial Department of Health, from University of Western Cape, South Africa and from Maynooth University, Ireland. Permission to engage with ART and PHC clinics was gained from the Regional Director initially and from each individual hospital/clinic/NGO.

Methodological, data and investigator triangulation processes (Guion, 2011) were adopted, to ensure validity of data. Initially patients consented to one-to-one, semi-structured interviews in their language of choice². Once an initial interview was complete, all participants were asked for further permission to continue engagement with them. For patients attending an ART clinic this involved a researcher who 'shadowed' them during interactions with the various health professionals (doctors,

² Of the eleven official languages in South Africa, Afrikaans, English and isiXhosa are the official languages of Western Cape Province. All of our research team are fluent in at least two of the three official languages.

nurses, pharmacists, ART counsellors, etc.)³. This facilitated observation and recording of patient experiences as they moved through the treatment pathway. Participants who were not engaged with services were asked to continue speaking to our researchers at their own discretion. Many patient participants gave permission for multiple follow-up meetings and shared their stories with us through conversations and interviews either at the clinic, at their homes, or at a place of their choice.

All formal interactions were digitally recorded, transcribed in full and, where appropriate, translated into English, which was the working language of all team members. A portion of the transcriptions were also then back-translated from English to Afrikaans or English to isiXhosa for verification of the translation process. Researchers had the opportunity to observe daily activities at each of the clinics over a number of months, and these were recorded in field diaries, which, along with interview notes, formed part of the data set. A thematic analysis was then conducted using cyclic three-step analysis - open coding, followed by axial coding, followed by selective coding (Strauss and Corbin, 1990) and AtlasTi was used to manage data sets. Finally, 22 'index patients' were identified whose cases typified the broader patient base in terms of their (non)adherence patterns. Four clear patterns emerged which were developed into brief representative case studies.

Once these representative case studies were completed a series of workshops was held where our data and provisional conclusions were presented to a cross section of participants (patients, health workers and NGO staff). This allowed participants the opportunity to give feedback about the findings, and to contribute to the interpretive process. Each of the patterns presented below was endorsed as an accurate representation of the lived experience of HIV-positive patients in the region.

Patterns of Adherence as Ethnographic Data

The case studies below are drawn from the 22 index patients, which were chosen as representative of patterns of adherence amongst our participants. They demonstrate the complex intertwining of political, economic, social-cultural, gender, and biological factors that impact the experience of living with HIV, as well as access and adherence to treatment. Many of these barriers cannot always be so clearly delineated, as they bleed into and influence each other. Others clearly have a top-down or bottom-up impact on how services are provided and on how service users access and understand their treatment. In concrete social-historical circumstances, these factors meet at the interface between logics and optics in the clinic and the resource constraints, expectations, even the resilience of real people. This interface exists in time, however, and very often the same behaviour, object, or idea changes its valence, sometimes dramatically, while people negotiate their relationship to different bureaucratic categories.

³ The healthcare worker's permission was also requested in such instances.

All participants have been anonymised and pseudonyms applied.

Benjamin's story, RIP (Adherent - Lost to Follow-Up):

The 'treatment holidays' patient (six months on/six months off, or nine months on/three months off)

28 year-old Benjamin was wheelchair bound when we were first introduced at an ART clinic; extremely weak and frail, he was living at his mother's home in the West Coast region. Benjamin had attended primary school but his family could not afford his attendance at secondary school. We subsequently met with him at his mother's home and at the clinic on numerous occasions.

Benjamin tested HIV and TB positive nine years previously, and was successfully treated for his TB before beginning antiretroviral treatment for HIV. His treatment initially caused upsetting side-effects - a rash on his chest, under his arms and on his private parts, and lumps on his leg, under the skin. No medication was made available to him for the side effects but his mother treated these with ointment and he persevered with his ART and slowly began to feel better. For Benjamin, as for others we spoke to, it was when he started feeling well again that he stopped taking his medication. Travelling to the Northern Cape Province he found temporary work until his condition deteriorated and he sought treatment at a local clinic. Unfortunately for reasons that were unclear to Benjamin, his initiation onto second line treatment was delayed in the Northern Cape continuously and in desperation he returned to the West Coast district where he had first been treated in the hopes of receiving second line treatment. This is where we met.

In the year after our initial meeting, Benjamin's progress on treatment was sporadic. His weakened condition made eating difficult and he was given nutritional supplements to drink with his medication. He was admitted to an isolation ward in hospital for five days after again contracting TB, although thankfully not a drug-resistant form. He was also diagnosed with epilepsy and was being treated for this condition while continuing on ART. Over the time we knew him, Benjamin reported feeling better and gradually was able to move about without his wheelchair. Under his mother's care, and with the clinic's assistance, his condition improved, although he remained silent, withdrawn and extremely thin.

Suddenly we received news that Benjamin had once again left the district to return to the Northern Cape. The staff at the clinic expressed disappointment as they felt that, although improved, his condition was not stable enough to once again leave their care, but he had not consulted with them before he left.

For reasons that are unclear, Benjamin once again stopped taking his ARVs when he got to the Northern Cape. We received word that he had passed away approximately one year after our first meeting.

Understanding Benjamin

A number of issues arising out of Benjamin's story have a bearing on his adherence pattern. While living under the close scrutiny and vigilant care of his mother, Benjamin's condition improved. Indeed, because of the social support available

to Benjamin, through his mother's care, the clinic were more inclined to provide additional assistance – they arranged to have his medication delivered to a clinic closer to Benjamin's home, and they provided nutritional supplements to Benjamin that were not given to other patients.

Once his condition improved, however, Benjamin repeatedly left his mother's care to return to his life in Northern Cape. Once there, he did not/could not access medication and his condition would deteriorate. Lima et al (2008) found that individuals migrating at least three times were 1.79 times more likely to be non-adherent than individuals who did not migrate.

It is not uncommon for patients to stop taking ARVs when their condition begins to improve. While medical staff stress that there is no cure for HIV, this is a problematic notion for some. This may relate to a straightforward matter of translation as for some local languages the word for 'treat', 'heal' and 'cure' is the same, and the distinction that is made in English does not translate properly. But the concept of a non-curable disease is also problematic, as Murray et al (2009) found in their study amongst Zambian women. Why should one continue to take medication if one is 'better'? For these patients, it is not until their condition deteriorates again (some months later) that they realise they need to go back to treatment. Nor is it particularly uncommon for this cycle to be repeated, deliberately or through unavoidable life circumstances. Such 'treatment holidays', when unplanned, can result in the emergence of HIV isolates resistant to ARVs (Katzenstein, 1997).

The inequity in treatment facilities in various parts of the country also has a bearing on Benjamin's adherence. The ART rollout programmes in the Western Cape and Gauteng provinces are renowned countrywide for being efficient and effective. Internal migration for treatment purposes is not uncommon. However, patients regularly leave the district for up to three months at a time (for seasonal farm work, during holiday periods or to attend traditional family events) and are often unable to access elsewhere the high levels of treatment they have come to enjoy in Western Cape. This poses difficulties for the clinics in each district. Western Cape clinics are reluctant to provide patients with bulk medication for an indeterminate period, unless they have established an exceptionally good working/treatment relationship with the clinic. For the clinic in the host communities, these 'visiting' patients can often not be accommodated because of lack of resources, shortages of medication, insufficient medical histories, etc.

Further challenges arise for patients who wish to transfer to another health facility when life circumstances change. These moves could be in pursuit of employment opportunities, forced by changing home situations, or simply wanting to start afresh with the new lease of life received from successful treatment. Whereas a province like the Western Cape has a well-resourced health system and boasts a computerised district health information system, the reality on the ground is that this system does not allow

for the ease of transfer of patients between facilities, even within the same district, because much of the patient information is still only in paper format (patient registers and folders).

Benjamin's recorded status with the clinic moved from 'adherent' to 'lost to follow-up' before word was received that he had passed away.

Gabriella's Story (Non-adherent – Adherent)

The 'partying' patient (six days on/one day off)

Gabriella was a 42-year old woman born in a rural part of the Northern Cape Province. She attended school there until the age of 10, but migrated to Western Cape in 1997 to find work. Her home was a shack in an informal settlement about 3km from her local ART clinic, where she lived alone. She had limited contact with her adult children who had moved away from her since discovering her HIV positive status.

Unemployed, Gabriella sometimes had casual work as a domestic servant for a few hours a week. Friends and neighbours offered food or money but she was reluctant to receive favours, preferring to do some small amount of housework for them rather than accept charity. Her absent boyfriend sent money erratically. When we first met it was 4pm in the afternoon and Gabriella had not eaten since breakfast the previous morning.

Gabriella became emotional as she recounted in vivid detail how she received her diagnosis for 'this illness'. Herself and her boyfriend both tested positive at the same time in 2008. 'They came back with coffee and two slices of bread' she said 'and the doctor came and looked at me...gave me a letter...told me that I am HIV positive'. Three months later, with a CD4 count of 145 cells/ μ l, Gabriella was started on ARVs.

Anxious to assure the researcher that she understood her treatment regimen, Gabriella took her tablets out of her bag to show which ones are taken at which times of day. The pills were muddy, as though they had been dropped or handled repeatedly. We established that adherence has not always been ideal and that Gabriella's pattern of adherence had changed substantially over the 18 months since she began treatment.

- Severe side effects (sore body, itching, dizziness, double vision, night sweats) in the early stages of treatment caused Gabriella to stop taking her medication properly. These side effects continued even after medication had been prescribed to relieve symptoms.
- At one stage Gabriella felt life wasn't worth living because her children didn't want to know her and she felt they didn't care, so she stopped taking her medication for a month. Gabriella went back on the treatment when she began to feel really sick.
- Numerous medical staff instructed Gabriella not to drink alcohol while taking her medication. Therefore, when she partied, or planned to drink, she did not take her medication. Nor did she take a double dose the next day; just skipped a dose.

Understanding Gabriella

Gabriella's case is typical of those patients whose adherence pattern changes considerably over the first year of treatment before settling into a less than ideal semi-adherent pattern.

No individual screening is conducted before initiation on first line ARVs to establish the potential extent or severity of side effects. Information regarding side effects is not always forthcoming, with Clinic counsellors and home-based carers expressing concern that patients will not take the medication if they know how severe the side effects might be. Instead, counsellors often 'drip-feed' information about side effects to patients as required, in the hope that they will not be discouraged. Patients who do experience side effects may stop taking their medication completely without ever returning to the clinic again. Where patients show willingness to persevere, the clinics will attempt to either treat the side effects, or provide alternative ARVs to reduce the impact. In Gabriella's case her pill burden increased substantially and the side effects were reduced, although not eliminated.

Depression and feelings of loss are not uncommon amongst patients given a diagnosis of HIV. As family relationships broke down, Gabriella stopped taking her medication because she said she 'wanted to just die'. Ammassari et al (2004) and Battaglioli-DeNero (2007) report on the negative impact of depressive symptoms on ART adherence. Ironically, Gabriella reported that it was after she stopped taking her medication and her condition deteriorated substantially, that her daughter began to re-engage and they started to mend their relationship.

Gabriella's pattern of adherence is extremely common amongst patients in the Western Cape region. Patients are repeatedly told that they should not drink while they are taking ARVs. There are several reasons for this: ARVs have the potential to cause liver toxicity and this is exacerbated by alcohol abuse; excessive alcohol consumption may increase the risk of non-adherence as people forget to take their medication, or the affects of the alcohol (or indeed recreational drugs) can inhibit the effects of ARVs. However, it is generally accepted internationally that failing to take a dose of ARVs, or erratic adherence, can cause more harm than taking ARVs with alcohol. Many of the nurses and counsellors currently working with HIV patients would previously have been trained in TB care, which requires that patients remain completely alcohol-free while taking their medication. This instruction appears to have been carried over to the treatment of HIV. Also, given the region's difficult history with alcohol and the high rate of alcohol abuse and foetal alcohol syndrome (FAS) amongst the local population (McKinstry 2005, London 2000, Olivier et al 2013), there is a genuine antipathy towards any alcohol use amongst many of the healthcare staff, and particularly nurses, in local clinics. Finally, the information currently provided to patients regarding ARVs and alcohol consumption could be interpreted as a medical care rationing decision on the part of the Government, rather than a decision based on clinical outcomes.

The clinics in the Western Cape use a 'teach back' technique to inform their patients in an effort to ensure that the patient is not a passive recipient of knowledge, but an active participant in the treatment process. This requires that the patient repeat back to the counsellor the information he or she has received, in order that the counsellor can see whether they have received the information correctly. Watermeyer & Penn (2008) describe the same process being used amongst pharmacists dispensing ARVs in Johannesburg. However, the manner in which patients repeat (verbatim, and with gestures) the information they have been given about alcohol avoidance, suggests that they do not fully comprehend the reason for avoiding alcohol. While alcohol is central to social life in the area, there is little tolerance on the part of health workers for even moderate alcohol use. One of our researchers witnessed an adherence counsellor refuse to recommend a patient for treatment on the basis that *her husband* drank alcohol. Gabriella only drank on Saturday nights, but was said she was 'afraid' to take her medication when drinking because she had been told it was 'very very bad'. Instead, as is the case with many others, her pattern of adherence was to take medication from Sunday to Friday only.

Gabriella was initially recorded as non-adherent, but, later, with little change in her drug-routine, she was labelled adherent.

Neville's Story (Adherent)

The 'playing' patient (5 ½ months on/two weeks off)

38 year-old Neville lived in his sister's home close to one of the ART clinics when we first met. He was introduced to two of our researchers by outreach staff who were concerned about his adherence. Both his parents were deceased and he had no partner. His sister had taken him in but their relationship was not good and money worries added to the difficulties. Having tested HIV and TB positive in 2008, Neville was granted a temporary (six month) social grant, which was due to end within 3 months of our meeting. This was a cause of enormous concern for Neville who repeatedly asked for help with retaining his grant. The grant paid for bills for himself and his sister and sometimes there was no money left for food. He generally borrowed money for food and was concerned about what would happen when the grant finished. His repeated question '*Wat moet ek maak, wat moet ek maak?*' (What must I do?), lent an air of desperation to his conversation.

Neville explained to us his treatment regimen. Taking a handful of tablets that he was carrying loosely in his pocket, he correctly identified the ARVs and explained (incorrectly) that he should take them at 12 noon and 7pm, and had already taken his TB meds at 7am this morning. In fact ARVs should be taken at 12-hour intervals and

the TB meds can be taken separately. He was also taking medication to counter side effects of the ARVs and had been told to continue taking it although he said it didn't work. It soon became apparent that Neville was attending three clinics in three different jurisdictions, though he could not clearly explain why this was the case. It appeared that one clinic was treating his HIV, another his TB and the hospital was treating Neville for cancer.

As we met with Neville over the following months, his situation deteriorated rapidly. The relationship between himself and his sister broke down completely and he was now living alone. He struggled to get money but sometimes got a bit of gardening work, which provided intermittent income. In addition, the hospital he had been attending had confirmed a diagnosis of cancer, but Neville was unable to provide any further information on this. His social grant was not renewed and the letter he received (which we were shown) did not explain why. He was given leave to appeal the decision of the SASSA (social welfare) and was planning to do so with the help of an outreach worker.

Understanding Neville

When patients are initially put on ART they most often present with a WHO Stage III HIV illness, i.e. they had at that time (pre 2010) a CD4 count of ≤ 200 cells/ μl .⁴ Patients are informed that they qualify for a grant as they are medically unfit to work. The CD4 count in itself does not render a patient medically fit/unfit to qualify for a grant. However, those with low CD4 counts in most cases experience a decline in their health – hence the reporting to the health setting. It is this concomitant factor that leads to the physician motivating for the disability grant on the basis of HIV defining illness. As the importance of the CD4 count is impressed on the patient in a variety of settings they come to believe, with some justification, that a CD4 count of ≤ 200 cells/ μl is *the* measure that determines their eligibility for a welfare grant. Patient CD4 count is checked every three months. It is envisaged that this check would indicate whether current treatment is working; soon after ARVs are instituted CD4 counts can be expected to rise and viral load reduced so low as to be undetectable. An increase in CD4 count would indicate that the person's immune system is getting stronger and HIV viral replication is suppressed. A stronger immune system would also indicate that the person is getting stronger (and potentially on the way to becoming economically productive).

The timing of a CD4 count blood test generally coincides with the renewal date of a social grant. For some patients, the grant has become a *de facto* poverty alleviation grant and they are unable to cope financially without it. They therefore begin to 'play' with their medication, in an attempt to 'manage' their CD4 count and thus retain their social

⁴ In July 2014 the National DoH changed its national guidelines to raise the threshold for initiation of ART at a CD4 count of ≤ 500 cells/ μl , effective January 2015. (SA DoH, 2014: 14). How this will impact patient's perception of their access to the grant is something that should be followed.

grant.⁵ The most common form of 'playing' with medication in such situations is to take pills only every second day; or to stop taking them completely in the days coming up to a blood test. The clinic checks adherence based on a medication count conducted during the normal check-up, but medication counts ignore medication complexity (Libby et al 2013) and do not confirm that a patient has in fact consumed the medication; merely that he/she has removed the medication from the package. We found patients in extreme circumstances will throw their medication away, flush it down the toilet or (in one case) keep it safely in a separate glass on a dresser.

Neville's attendance at a variety of different healthcare settings also served to confuse him with regards to his medication. The local ART clinic that Neville attended had considerable difficulties with retention of medical staff in the previous two years. This is in large part due to a systems failure within the organisational structure of the rollout programme of the district. The result is that over a six-month period in 2009 there were five different doctors in the clinic and for long stretches of time the clinic had no doctor at all. Over the period in question the clinic staff reported that up to 100 patients had been 'lost to follow-up'. Local newspapers carried reports from patients who expressed their concern at the breakdown in service at this clinic, and many patients sought services at clinics in neighbouring jurisdictions. The failure of the clinic service itself presented a barrier to adherence for the patients in this instance. Neville was caught up in this situation, unable to find a doctor who could cater for all his needs and receiving contradictory information regarding his treatment regimen.

Poor service delivery, low levels of treatment literacy, an extremely complex treatment regimen and the withdrawal of a social grant resulted in a lack of adherence for Neville. A pattern of adherence that was good for five and a half months, then poor for a few weeks, resulted and is typical of people 'playing' with meds in an attempt to retain a social grant.

Neville was recorded as being adherent by the clinic.

Ophelia's Story (Non-adherent – Adherent)

The 'secretive' patient (skips two or three doses of medication per week every week)

Our isiXhosa-speaking researcher first met Ophelia at her home having received prior permission to call via an outreach worker. Ophelia was a 41 year-old woman who lived with her boyfriend and her daughter in an informal settlement about 1km from one of the clinics. She was unemployed and had no income. Ophelia's older child lived away from home and had menial work but was not in a position to provide any financial assistance to her mother. Ophelia relied solely on food parcels from the local home-based care centre, and handouts from friends. She tested HIV-positive in 2007 and she had not disclosed her status to her partner because she believed him to be HIV-negative.

⁵ For more on this see Natrass (2004) 'Trading-off income and health: AIDS and the disability grant in South Africa'.

She had also been successfully treated for TB.

When initially diagnosed, and before commencing ARVs, Ophelia suffered from *ibande* (shingles). She described severe symptoms including pain and 'itchiness on the inside' and was given painkillers, sleeping tablets and calamine lotion by the clinic, none of which eased her condition. She attended a traditional healer who gave her some *muti*, that she took in addition to her other medication, but the *muti* caused diarrhoea so she stopped taking it and has not returned to her traditional healer.

Ophelia was prescribed Bactrim and Vit Bco, for three months during the work-up period for ARVs. However, she left the jurisdiction of the clinic to attend to family matters in *emaXhoseni* (Eastern Cape rural areas) and because of this was deemed to be a risk for adherence on ARVs when started.

In an effort to convince the clinic to support her application for a disability grant, Ophelia threatened not to take her medication unless she 'got the pay'. Her grant was never processed due to a series of bureaucratic errors and Ophelia was particularly aggrieved that, despite a CD4 count of 4 (four) cells/ μ l, she still received no financial assistance from the state.

Once ARVs were initiated, side effects including nausea, vomiting and a rash were constant. She attributed this to taking medication on an empty stomach but said when she told the clinic she had no food they didn't care. At the time of our first meeting Ophelia had not taken her medication properly for the previous two months. This was in part due to the breakdown in her relationship with the clinic who publicly berated and humiliated her for not adhering to the treatment regimen pre-ARVs. She was angered by their apparent unwillingness or inability to help with the grant application. The nausea and vomiting she experienced also discouraged her from full adherence. In addition, in an effort to hide her status from her boyfriend, Ophelia kept her medication at the home of her older daughter and could not always get to her daughter's home to collect the medication as required

Understanding Ophelia

A number of factors impacted on Ophelia's adherence behaviour but her pattern of adherence was such that she missed/skipped her medication twice or three times per week.

The grant application system presented bureaucratic obstacles impossible for Ophelia to overcome without assistance. This assistance is often given by the clinic, but given the breakdown in her relationship with the clinic, such assistance was not forthcoming. A series of errors with the application (no doctor's stamp, a shortage of clinic letterheads, Ophelia's inability to provide a utility bill) prevented it from even being processed despite the fact that she was clearly eligible under all the necessary criteria to receive funds. Her resentment with this situation was such that, at one stage, she was partly

refusing to take her medication as a protest, although since she struggled to articulate this clearly her protest went unnoticed.

Publicly berating patients for non-attendance or poor adherence behaviour is a common occurrence in ART clinics. Our researchers have been present when patients have been shouted at and while clinic staff have conducted telephone conversations with patients, using their name and personal details, all within view/earshot of a full waiting room. Lack of attention to issues of confidentiality has also resulted in patient files being left open for other patients to see and, in one extreme case, a patient berated continuously for non-adherence because the clinic had confused her with someone else of the same name. The breakdown in trust and resulting poor relationships have a bearing on adherence as patients will often refuse to attend after such an incident, for fear of receiving another public rebuke. As one patient put it 'She tells me I will die... Just die! I know I'm going to die but sometimes I have a problem.'

Finally, the fear of disclosure to a partner, workmate or other family members often causes patients to skip their medication rather than take it in view of others. One of our participants skips his medication once a week, when working on a specific shift with what he considers a suspicious co-worker. Conscious of the rattle of medication in a plastic pillbox, many patients prefer to carry their pills in plastic bags or loose in their pockets rather than have their status 'betrayed' by rattling pillboxes. This often results in a degradation of the pills as they become dirty and/or chipped. In cramped living conditions it is difficult to have secrets from loved ones and Ophelia's decision to leave her medication elsewhere in order to maintain some confidentiality had an enormous bearing on her health.

Ophelia was originally reported as 'non-adherent' but, still only on a partial usage schedule, she was, by the end of our research, recorded as 'adherent' by the clinic.

The Membrane Between the Clinic and the Community

At one level, these four cases add to a well-established record in the literature on HIV and ART concerning the unhappy alchemy of how resource scarcity, different expectations of the clinical encounter, a conflicted political history, and ways that various elements (both physical and human) structure how patients come to therapy (as well as the expectations people have of this treatment) in local moral worlds. Once on medication, however, studies on the temporality of ART adherence tend to bifurcate, with those in the Global North, largely stressing the psychotherapeutic aspects of choice, such as 'choosing life' (Gray 2006:52) or 'sticking to it' (Burton and Hudson 2001) or treating the co-morbid mental illness that interferes with decision-making (Daughters et al. 2010). In the Global South, on the other hand, the challenges in front of adherence as a process still (understandably) tend to be situated in political economic constraints and how brutal limitations impact

local notions of agency (for a review, see Brandt 2009; see also Siu et al. 2013 and Ezekiel et al. 2009 among many others). Despite long-standing calls (and even announcements) to combine such approaches (e.g., Parker 2001) in HIV research, in the Global North the internal psychic economy is seen to be decisive in ART adherence and, in the South, it is generally the ways that the straitened material economy or the local cultural topography of gender and class inhibits choice. In neither body of literature is the temporality of adherence to ART granted a decisive role in theory. Thus, while we have in Anthropology strong critiques of abstract choice, there is still a hesitation to explore agency as a processional phenomenon that emerges (and alters) over time in concrete social-historical circumstances (for a considered exception to this statement, see Irving 2011).

The fluidity of these categories, of course, has real-world consequences for our understanding of ART. In these four cases, for example, at the beginning of our research Benjamin and Neville were recorded as 'adherent' but within two years Benjamin was 'lost to follow-up' (even though we and the care-workers knew where he was in a geographic sense), and he subsequently died. Meanwhile, Neville remained 'adherent' although his use of medication was less than ideal. Gabriella and Ophelia on the other hand, both went (in the view of the clinic) from 'non-adherent' to 'adherent' even though they presented quite different patterns of consistently partial use. Whatever else these observations demonstrate they show that neither 'access' nor 'adherence' is a state, something that someone has/does not have or is/is not doing.

Instead, adherence is negotiated continuously, sometimes on a week-to-week basis – very often on grounds in-between 'medical' and 'non-medical' considerations, such as understandings of how 'healthy' one can be while still maintaining access to the social grant available to patients who are too sick to work. In many settings in our fieldwork, for example, real unemployment rates are in excess of 80%, thus the 'supplemental' income provided by the government for some HIV sufferers represents a significant improvement in household budgets. In the end, the picture that emerges is one in which HIV-positive individuals are often listed as 'adherent' when they are in fact experimenting with different schedules of ARVs, often while using complementary therapies in order to survive in circumstances that can be very close to overwhelming. At the same time, many of the 'non-adherent' (and even some of those who are ostensibly 'lost to follow-up') are still taking a significant amount of ARV medication.

There is of course a significant global risk in the widespread, but inconsistent, use of ARVs; that is the potential emergence of super-resistant strain(s) of HIV, something that could conceivably set the clock back to the early 1990s, or even the 1980s, for everybody.⁶ While we do not wish to underplay the extraordinary success of the South African scale-up of ART, even where there has been the most dedicated staffing and

⁶ *The introduction of fixed dose combination therapy in 2013 has been heralded as something that should assist with adherence, but we note that very few people with whom we interacted found the schedule of the drugs per se to be a significant barrier to adhering to their treatment regimen. If scheduling as such is decisive, however, then we would predict an even higher failure rate on second-line treatment.*

monitoring – such as the work of Boulle et al. in Khayelitsha – about 10% have been lost to follow-up and over 14% are on second-line therapy because of adherence issues with their first-line drugs (Boulle et al 2010). The Western Cape in the Republic of South Africa, while a resource-poor setting, is probably the most 'developed' infrastructure for HIV treatment on the continent: it is where most of the assumptions about 'adherence', birthed in the industrial economies of the North (shaky as they may be for marginal populations in those settings) should best work. It is very hard to understand how we continue to track the success of programmes that in less than a decade scaled up a treatment regimen that serviced thousands (in very specific parts of the world) to one approaching ten million (delivered in nearly every part of the world) (UNAIDS 2013, WHO 2013), through these three simple categories – 'adherent', 'non-adherent' and 'lost to follow-up' – when the fluid nature of such categories are part of the tacit knowledge of most researchers and clinicians in this field.

Conclusion

Almost two decades after Farmer's clarion call to understand, 'the degree to which patients are able to comply with treatment regimens is significantly limited by forces that are simply beyond their control' (2001 [1999]), researchers in Global Health, International Health, Medical Anthropology, and beyond have recognized that structural violence imposes brutal limitations on a notional standard average subject making rational choices to take their meds and get better. Indeed, the term 'structural violence' has been absorbed into the working lexicon of practically all researchers in HIV and AIDS. Yet, after undeniable progress in tackling the plagues that were 'new' in the 1980s and 1990s, we find subjects and local moral worlds that are still resistant to easy comprehension or straightforward manipulation. To put it in perhaps more provocative terms: humans strive to regain (or help others regain) health, but not just as healers and sufferers please, and certainly not at a time and place of their own choosing. Resource scarcity and structural violence impacts individuals, families, and communities simultaneously but often in very different ways, even within the same neighbourhood. If treatment comes with an income supplement, for example, then its 'success' results not only in a now-healthier individual, but also in renewed distress of a family unit, even as a reinvigorated body emerges into a new horizon of local possibilities and limitations (see Mfecane 2012). In a similar fashion, powerful drugs enter local moral worlds at a particular historical moment, bearing specific valences. In South Africa, as in most of the Southern roll-out of ART, they often come coded as gifts with all the social-building and social-imperilling qualities that this term entails. They also confront indigenous forms of pharmacological reasoning that are only crudely labelled 'folk' and 'traditional', often with unforeseen results (see Larkan, van Wyk and Saris 2010). Yet, in the compiling of

'hard' data to measure 'success' and 'sustainability' such complex processes are recoded as discrete events, and significant decisions about programmes and populations ride on how these 'moments' are tabulated and analysed. As Biehl (2007:385) notes, "Numbers and statistics are intensely political," but the politics involved change over time and vary with the scale of the analysis. While this issue of the production of evidence has exercised scholars in Global Health for some time (see among many others, Pisani 2009 and Kleinman et al. 2008), we feel that the explosive expansion, the life-long nature, and the high individual and population costs of failure of ART all argue that this perspective needs to be more centrally positioned in longer-term ethnographic research on 'adherence'.

In making this case, we have no desire to further remove HIV treatment from the rest of any health system in resource-poor settings; indeed we are arguing the opposite. Both Harries et al (2006) and Bax et al. (2015), for example, convey some of the complexities of scaling up ART in resource poor settings, highlighting the need to ensure that other health services do not suffer in the attempts to improve HIV treatment. It is clearly health *systems* that need investment and overall strengthening. This insight is becoming obvious in the renewed Global Health/International Health interest in the immense burden of chronic and non-communicable diseases in resource poor settings (e.g., Alwan 2010). This insight, though, should be more expressly connected with a large literature on how issues of governmentality and long-term connection with medication and/or repeat clinical visits exist in other contexts (Leonard, Greene and Erbeling 2007, Saris 2008 and Montoya 2011, among many others). We would like to see the problem of ART adherence centrally positioned in this reinvigorated appreciation of health systems. In a sense, this call harkens back to themes in Critical Medical Anthropology that never went away (see Baer, Singer and Susser 2013 [1993]), but now we now confront the remarkable (if still partial) success of sheer access to drugs, and the reality of the immense diversity of the complex social-moral worlds into which these pharmaceuticals have been woven on an unprecedented scale.

To keep on top of this challenge, we will need to know a lot about a lot of things all at once – how people understand access to ART; but also much more precisely how they are taking their medication on a day-to-day through year-to-year basis, and, importantly, how they are monitored, especially, the specific mechanisms through which this knowledge is tabulated and disseminated. We will want to know about health services and health messages (and how to improve them), but we will also need to know how certain social-medical issues like how alcohol exist in extremely complex ways in historical memory and local moral worlds (see Mfecane 2011). We want to improve data-collection and analysis of health systems, but we need to understand the complexities of translation between communities of speech, language, class, and professional expertise (see Wood and Lambert 2008), as well as how this data is tabulated and scaled up in as fine-grained a way as is feasible. Most importantly, we need to do this rigorously and consistently

over long periods of time. This is precisely the sort of knowledge good, long-term ethnographic work generates. Living with HIV means living with and on ART, and such therapeutic citizenship is no less conflicted and ambivalent as 'citizenship' in any other collectivity. We require many more researchers who track between the people producing such categories of inclusion and exclusion and those who inhabit them (sometimes all of them) at very different scales and at different moments in time. Such work is necessary both to safeguard the enormous gains that have been made in the past decade or so and to protect against an unseen and unappreciated global experiment where potentially millions of bodies with sub-optimal ART unnecessarily (and in a public health sense, very dangerously) sicken with resistant new sub-types of the virus. It is also a critical piece in the puzzle to better understand how the three clean bureaucratic categories of 'adherent', 'non-adherent', and 'lost to follow-up' ultimately fit the complex biosocial realities that we wish to both analyse and improve.

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