Antiretroviral Adherence in South Africa: Are we Burning our Bridges?

Prof Alta C van Dyk

Department of Psychology

ABSTRACT

The national antiretroviral treatment programme in South Africa commenced in 2004 and today we have one of the largest antiretroviral programmes in the world. There is, however, growing concern about ARV adherence, the development of drug-resistant HIV and drug failure. Issues addressed are: treatment adherence following the national antiretroviral rollout in South Africa; and barriers to adherence. The general conclusion is that rates of ARV adherence in South Africa are probably similar to rates of adherence to treatments for other chronic diseases, namely between 40% and 50%. Various service-related, psychological, social and other barriers to adherence are discussed. Suggestions on how to assist ARV users to overcome adherence challenges and to reach the required adherence level of 90% or more are made. If we cannot achieve this, we might face a huge health crisis in future and are indeed burning one of our last bridges to stop the Aids epidemic.

INTRODUCTION

On World Health Day in April this year (2011), the message of Dr Margaret Chan (Director-General of the World Health Organization) was loud and clear:

> "The world is on the brink of losing its miracle cures. At a time of multiple calamities in the world, we cannot allow the loss of essential medicines to become the next global crisis" (WHO, 2011).

This comment of Dr Chan should be seen in the light of a growing concern by the World Health Organisation regarding the alarming increase of drug-resistant micro-organisms – usually the result of inappropriate and irrational use of medicines. We are all familiar with drug-resistant tuberculosis (or MDR TB). In just the past year, nearly half a million people worldwide developed multidrug-resistant TB, and a third of them died as a result. Eight thousand new MDR TB cases occur in South Africa per year. We also do not need to be reminded of what happened when extensively-drug

resistant TB (XDR-TB) was diagnosed in Tugela Ferry in KZN in 2005, where all the patients died within 16 days after diagnosis. Extensively drug-resistant TB has since been reported in 64 countries (WHO, 2011).

This concern about the development of drug-resistant micro-organisms also applies to the HIV field. The **key question** I therefore wish to address today is:

> To what extent may the rapid scale-up or expansion of ARV usage in resource-limited countries contribute to adherence problems and the development of resistance to ARVs?

I will attempt to answer this overarching question by addressing three related sub-questions:
1. How does non-adherence to ARVs impact on the development of HIV drug resistance?
2. What does adherence look like in South Africa after the national ARV roll-out started in 2004?
3. Which barriers exist in adhering to ARVs and what is the impact of these barriers on adherence levels in South Africa?

Before giving attention to these three questions, I would like to give a brief overview of the history of ARVs in South Africa.

HISTORY OF ARVs IN SOUTH AFRICA

Years of denial, blaming, moralising and inaction finally came to an end in the watershed year 2003, when the South African Government finally approved a national programme to make antiretroviral drugs publicly available to all HIV infected people who qualified for treatment. Unfortunately the damage done by the government's inaction was irreparable and many believed that the national rollout was "too little too late". If this decision was made only three years earlier, an estimated 330 000 lives could have been saved (according to AbdoolKarim& Baxter, 2010: 42).

The most tragic oversight was probably when the government refused to provide antiretroviral medication to pregnant women to prevent mother-to-child transmission of HIV in 1998 – four years after it was proven to be successful in the USA. That ARVs were urgently needed in South Africa was illustrated by the finding that HIV infection in pregnant women increased from 4.3% in 1994 to an estimated 17% in 1998. When the South African High Court finally ordered the government in 2002 to make Nevirapine available to pregnant women, HIV prevalence in pregnant women had then already risen to 24.5%.

Today, South Africa has the largest antiretroviral therapy programme in the world with a 54% coverage and with 1.5 million people on ARVs (UNAIDS, 2010). In addition to this, the pressure on government is increasing to revise their ARV policy and to treat more people earlier since the publication and active media coverage of the "Treatment as Prevention" strategy in July this year by Montaner (2011). The "Treatment as Prevention" strategy is based on research findings which showed that by expanding ARV coverage (that is, putting more people on ARVs earlier) the communal viral load will be lowered and this in turn is associated with declining numbers of new HIV infections. The strategy is based on the widely accepted principle that the concentration of viruses in the blood is a key driver of HIV transmission.

Researchers are however becoming increasingly concerned about antiretroviral adherence levels in South Africa since the national rollout commenced in 2004 (Mills, et al., 2006; Kagee, 2008). It is widely accepted in the scientific community that an adherence level of at least 90% is necessary to suppress the virus sufficiently, to increase CD4+T cell counts, to avoid the risk of mutation, and to prevent the development of drug resistant strains and drug failure (International Health Institutions, 2011; World Health Organization, 2011). In practice it means that patients must be motivated to commit to life-long therapy and to maintain extremely high levels of adherence to therapy over many years.

Before turning my attention to ARV adherence in South Africa in an attempt to answer the question: "Are we burning our bridges?" with poor ARV adherence, allow me to explain why and how resistance develops. This brings us to sub-question 1: How does non-adherence to ARVs impact on the development of HIV drug resistance?

DRUG RESISTANCE

The development of resistance is a natural biological process that will occur, sooner or later, with every drug (Chan, 2011). The use of any antimicrobial drug forces microbes (that is bacteria, viruses and some parasites) to either adapt or die. Microbes which adapt and survive carry genes for resistance, which means that the medications which were effective before will no longer have an effect on these microbes. This natural process of resistance development has been vastly accelerated by human practices such as mismanagement of antibiotics, prescribing inferior drug regimes, treatment interruptions and non-adherence.

There are two main factors impacting on the development of drug resistance in HIV:

1. the high genetic variability of HIV (or its ability to mutate rapidly); and
2. the relative "fitness" of these variations (or mutations) in the presence of antiretroviral drugs.

High variability of HIV

HIV has a very high replication (or reproduction) rate – up to ten billion new virions are reproduced daily in an untreated person's body. During this replication process of HIV, approximately five mutations are introduced every time an HI virus replicates – which is an extremely high rate of mutation (Williamson & Martin, 2010: 121). This high rate of mutation is due to the fact that the replication of HIV is (for various reasons) an extremely error-prone process. This implies that two types of viruses are constantly being produced in the body of an untreated HIV-infected person: the original "wild type" virus, as well as some mutants – produced by the errors during replication.

But how do these mutants lead to resistance to antiretrovirals (or ARVs)?

To answer this question, I first need to explain the role of enzymes during viral replication, and how these enzymes are targeted by ARVs.

Three important viral enzymes are involved during the various stages of the replication of HIV: Reverse Transcriptase; Protease; and Integrase. Most of the antiretroviral drugs currently available are designed to inhibit or block the actions of these viral enzymes. ARVs are highly specific to the enzymes they target. We can explain this as a lock and key system. Each ARV (or key) fits only one specific lock (or enzyme). When mutations occur, the viral enzymes also change and the ARVs targeting these enzymes will no longer have an effect on this specific mutation. Or to use our metaphor, the key (or ARV) will no longer fit the lock (the changed enzyme). This is the point where we say that HIV drug resistance has developed – and where ARVs will have no effect on the mutant viruses.

Relative "fitness" of mutants

The development of drug resistant viruses also depends on the relative fitness of mutants. I will illustrate this by explaining what is happening with mutants in the body of an untreated HIV-infected person; a person on ARVs who optimally adheres to the medication regime; and a person who defaults and cannot reach an adherence level of at least 90%.

Untreated HIV-infected person

The majority of viruses in an untreated HIV-infected person's body will be wild-type viruses. There will also be mutants, but these mutants generally have reduced fitness because they are at a competitive disadvantage relative to the wild-type viruses. They will thus remain in the minority and their transmission rate will be lower.

Optimum adherence to ARVs

When antiretroviral medications are introduced, the ecology of the virus population in the body changes dramatically. The wild-type virus will be repressed, and if the patient adheres to the medication optimally, reproduction of the wild-type virus is severely hampered. Mutant viruses will have difficulty in surviving due to their low numbers and reduced fitness. This is the ideal point in adherence to ARVs where the viral load is undetectable and the immune system gets the opportunity to replenish itself.

Non-adherence

But what happens if the person does not adhere to their ARVs or if an insufficient medication regime is used (for example, one drug instead of three)? The majority of the wild-type viruses will still be killed due the selective drug pressure, but viral suppression will be insufficient. Mutations will gain relative "fitness" because there are not many wild-type viruses left to compete with. Some of them may now develop an increased capacity to replicate and can develop into the dominant population in the person's body (Wood, 2010). If ARV treatment is changed to a more potent regime, the mutants will decrease again, but they are archived in memory cells and can re-emerge if ARVs to which they are resistant are used in future (Bennet et al., 2008).

The development of drug-resistant viruses has serious implications, not only for the individual, but for treatment in general. Resistance to one drug may result in cross-resistance to all other drugs in that same class. This is because ARVs in the same class target the same enzyme – and this enzyme has now changed due to mutation. It is especially in the NNRTI class of ARVs (which is part of our first-line treatment regime in South Africa) that resistance can develop extremely fast – treatment delays as brief as 48 hours may result in resistance in the case of some of these drugs (Bennet et al., 2008). Some of the drugs in the NRTI class (like Tenovovir, which is now used in South Africa in combination with NNRTIs) as well as drugs in the PI category are more "forgiving" when dosages are skipped. Drug-resistant HIV strains can also be transmitted to other people (under certain conditions as highlighted on the slide) with the consequence that the drugs will also not work for them.

When treatment failure occurs (due to resistance) the only option is to switch to a new ARV regime - targeting different enzymes or processes during viral replication. These regimes are usually much more expensive and what do we do when we run out of options and all possible classes of ARVs have been exhausted?

It is then that we will reach the stage of which Dr Chan said: “No adherence today, no cure (or in the case of ARVs no treatment) tomorrow.” That is when we will have burnt our bridges and will lose one of our most useful weapons (ARVs) against the Aids epidemic.

After this explanation of how HIV drug resistance develops, we need to consider our second question: How serious is the problem of adherence in resource-limited countries, and more specifically, in South Africa?

CAN PEOPLE IN RESOURCE-LIMITED COUNTRIES ADHERE?

In earlier writings on adherence, the question was often asked: “But can people in Africa adhere”? And the answer is “yes” - if patients are properly prepared and are exposed to various adherence interventions. Studies done in South Africa, Uganda and Botswana between 2004 and 2008 by various researchers (such as Coetzee, et al., 2004; Hardon, et al., 2007; Mills *et al*., 2006; Nachega, 2009; Weidle et al., 2006) found very high adherence levels (based on pill counts and confirmed by viral load testing). These researchers came to the conclusion that drug adherence in healthcare settings in developing countries may be comparable to that seen in developed countries.

Studies reporting high levels of ARV adherence should however be interpreted with caution and cannot be generalised to the broad population of ARV users after national scale-up of treatment (Brown, MacIntyre& Trujillo, 2003; Kagee, 2008; WHO, 2011). Most of the adherence studies have been done for only a limited period of time under strictly controlled conditions – such as clinical trials or specific programmes where ARV-treatment support and/or psychological support was provided. Some of these were group education, extensive counselling, personal drug adherence planning, treatment supporters, weekly visits by field officers, and weekly home delivery of medications. Most resource-limited countries do not have the resources and infrastructure to keep up this kind of ARV support.

A general conclusion from the literature is that rates of drug adherence among ARV users are

probably similar to those of patients taking drugs for other chronic diseases, namely between 40% and 50% adherence — a level unacceptable for patients on ARVs (Lerner, Gulick&Dubler, 1998; Cheever & Wu, 1999; Skhosana, Struthers, Gray& McIntyre, 2006). If adherence to ARVs is indeed this low, we may have increasing problems with ARV resistance and will be faced with great challenges in terms of the management of HIV infection in future.

But what is the position with adherence in South Africa after the national ARV rollout started in 2004?

Antiretroviral adherence in South Africa

I conducted a survey in 2009/2010 to look at adherence levels in a post-rollout South Africa. My adherence study included 450 antiretroviral users who received their ARVs from over 300 different clinics and hospitals in rural as well as urban areas across the country. By selecting only one or two ARV users from each service provider, the influence of special adherence programmes or strengths and problems that might be attached to individual clinics, were avoided.

I used the patient self-report method by asking participants to imagine a typical month in their lives on ARVs and to indicate on a scale what percentage of time they adhered to their treatment programme. Although some studies have shown that patient self-report overestimates adherence by as much as 20%, patient self-report is still one of the best methods to measure ARV adherence, according to the National Institutes of Health (or the NIH) in the USA (2011: 121). The NIH further reported a significant correlation between patient self-report and viral responses.

Details about the procedure, measuring instrument and statistical analysis of the adherence study were published in Van Dyk 2010 and 2011 and will not be repeated here.

Background sketch of participants

The mean age of participants in the study was 35.6 years. The majority were females (68%) and lived in rural areas of South Africa (42%).The education level of the participants was generally high (with 27% having post-secondary school qualifications). Forty percent of the participants were unemployed. The average time participants were on ARVs was 29.2 months. The only demographic variable that significantly correlated with adherence, was age, with younger participants (<30 yrs) finding it harder to adhere than older participants (cf. Rao et al., 2007).

RESULTS

Self-reported ARV adherence

Only 40.1% of the ARV users who participated in the study reported adherence levels of more than 90%. The majority (almost 60%) could not reach optimum adherence levels, with 49% reporting adherence levels between 70% and 90%, and 10.9% being unable to reach adherence levels of 70% – an adherence level which is considered as extremely low in the ARV field (Bennett et al., 2008; Hardy, 2003). If the over-estimate of 20% for self-reported adherence is taken into account, actual adherence might even be lower.

The finding that only 40% could reach the target for optimum adherence as set out by the World Health Organization confirms suggestions by other researchers that rates of ARV adherence are probably similar to rates of adherence to treatments for other chronic diseases (Lerner *et al*., 1998; Cheever & Wu, 1999). Although the results of the ARV adherence study cannot be generalised to the South African population of ARV users as a whole, it probably gives at least some indication of what is going on in South Africa since the national ARV rollout in 2004.

So what can we do to assist ARV users to reach the 90% or higher adherence target as set by the World Health Organization? In an attempt to answer this – which also brings us to our third question, I asked the participants what barriers they experienced in adhering to their ARVs or alternatively what made it easier for them to adhere.

Barriers to adherence

Principle Component Analysis extracted the following components (or barriers) that significantly contributed to non-adherence in the study:

- Practical, environmental and service-related problems;
- Lack of support by healthcare workers;
- Personal and psycho-social factors;
- Lack of ARV-adherence knowledge;
- Perceived lack of control over personal health; and
- Stigma and discrimination.

Practical, environmental and service-related problems

Many of the problems identified in my adherence study (and confirmed by others) had to do with the ARV treatment regime as well as with practical, environmental and service-related problems

(cf. Skhosana*et al*., 2006; Aspeling& Van Wyk, 2008; Kip *et al*., 2009; Nachega, 2009). ARV users who had to take a large number of pills at different times in the day struggled significantly more to obtain optimum adherence than users on an easier treatment regime. All efforts should therefore be made to prescribe simpler regimes to make adherence easier.

Another common regime-related reason for non-adherence was side effects (also cf. NIH, 2011). Sixty percent of ARV users in the study experienced side effects at one or other stage in their treatment history. Of those ARV users who reported side effects, 64% could not reach the optimum 90% (or higher) adherence level. Many simply stopped their medication until they felt better. Treatment regimes, their possible side effects and ways to cope with these must be discussed with every patient on ARVs.

The hidden costs involved in being on ARVs also proved to be a problem for many ARV users. It is of great concern that 37% in the non-adherence group and 21% in the adherence group often did not have enough food to eat and could therefore also not take their ARVs – especially those medications with food requirements. Fifty two per cent of ARV users who could not reach a 70% adherence level, indicated that they live in poverty and often go hungry. Finding transportation or money for transport to collect their ARVs posed a further problem for 30% ARV users in the non-adherence group, and 14% in the optimum adherence group (also cf. Hardon*et al*., 2007; Aspeling& Van Wyk, 2008; Kagee, 2008; Nachega, 2009).

There was a difference in the way ARV users in the two groups (non-adherence and adherence) dealt with these practical and financial issues: Those who optimally adhered to their ARVs (who were also often unemployed and complained of hunger) acted pro-actively and took control over their situation. They reported, for example, and I quote: *"I did piece-jobs to get enough money to get my ARVs"; "I asked a friend for bread"*.

ARV treatment clearly involves much more than the cost of ARVs. Patients in the public sector often need assistance with monthly food parcels and transportation vouchers – which opens up great opportunities for community-based, faith-based and other organisations.

The results of the adherence study further indicated that the healthcare system is often failing to sustain ARV treatment: Twenty percent of ARV users in the non-adherence group reported encountering stock-outs and having to return home without collecting their medication – often only being able to go back a week later due to transport problems or because they could not get time off

from work. An average clinic visit in South Africa consumes a full working day, according to Wilson and Fairall (2010). Only 4.5% of ARV users in the optimum adherence group gave stock-outs as reasons for skipping dosages.

Many ARV users related stories about healthcare workers being on strike, or being on holiday without backup plans or personnel to assist them. For example one participant reported: *"They went on strike and they said it is for our own good — they are fighting for more ARVs. But how is it good for me if they send me home without my ARVs?"*

Stock-outs and unsustainability of ARVs for whatever reason, is unacceptable. And the answer does not lie in putting fewer people on ARVs – the solution should be sought in supporting more people more effectively. Some suggestions made in the literature are: more mobile ARV clinics; sites closer to where people live and work; more nurse-based treatment centres; three-month prescriptions for treatment-experienced patients who show optimum adherence; and follow-up home visits (Van Dyk, 2007; Kip et al., 2009; Weidle, et al., 2006).

An even more disconcerting reason for not adhering to her ARVs was given by one patient (with a self-reported adherence level of 60%) who explained how she deliberately "managed" her CD4+T cell counts to remain low. She did it by sometimes skipping her ARVs, because *"If my CD4s go too high, they take away my grant because they say I am healthy enough to work."* Government policy issues, or the perception of these policies, need urgent attention.

Healthcare worker support

Support by healthcare workers was another variable that significantly predicted ARV adherence. Participants were generally satisfied with the information, care, support and respect they received from their healthcare workers. However, 13% in the non-adherence group felt unsupported in their day-to-day efforts to adhere and complained that test results (like CD4+ T cell counts) were often not explained or shared with them.

About 20% of ARV users in the non-adherence group said that they were not properly prepared by healthcare workers to go on ARVs. One participant with a 60% adherence level said that the healthcare worker made her feel as if *"I have won a prize or the lotto or something because I qualify for ARVs – but nobody told me how difficult it would be."* Other ARV users in the non-adherence group indicated that they never had the intention in the first place to take or adhere to ARVs: They were coerced by healthcare workers and in some cases "forced" by sex partners to take

ARVs.

Healthcare workers should not underestimate the importance of treatment preparation programmes; evidence of readiness and ability to adhere; individualised action plans to rectify problems; regular patient follow-up; and assessment of adherence with every clinic visit.

Although to have a treatment supporter is no longer a condition for enrolment into a government ARV programme, treatment supporters should be considered for all ARV users (if it is safe for a person to have one). The important role that treatment supporters can play in assisting ARV users, was confirmed by the significant correlation that I found in my study between having a treatment supporter and reaching optimum adherence (substantiated by Weidle*et al*., 2006; Kip *et al*., 2009). Of the 26% of patients who did not have treatment supporters, 76% could not achieve adherence levels over 90%.

Personal and psychosocial factors

Various personal and psychosocial factors impacted negatively on ARV adherence. Barriers to adherence of great concern are alcohol abuse and depression. Of those ARV users who defaulted on their treatment, 21% and 24% said that they often forgot to take their ARVs when they used alcohol or when they felt depressed respectively. In the optimum adherence group, only 5% and 4.5% participants gave alcohol use or depression as reasons for non-adherence (also cf. Bottonari*et al*., 2005; Kagee, 2008; Kip *et al*., 2009; Nel& Smith, 2006).

One participant in the study with an adherence level of 10% confessed that he "believes that the pills were sent to kill me, so when I have these feelings that they are sent to harm me, I stop taking them for a while." This begs the question if healthcare workers are properly trained to screen and to refer patients with mental health and other problems for treatment for these conditions before commencement of ARV treatment.

Further psychosocial barriers that predicted low ARV adherence levels were forgetfulness, lack of planning, communication problems, and treatment fatigue. An unacceptably large portion of ARV users in the non-adherence group (24%) had run out of ARVs in the past – not always due to service provider problems, but often because of insufficient planning on their part. Bad planning was probably one of the reasons why 14% of non-adherers said that they have shared their ARVs with friends in the past. In the adherence group only 3.4% reported running out of ARVs due to bad planning, and only 6% shared their ARVs with friends in a crisis situation.

Long-term planning, for example to get enough ARVs when they went on holiday, or when they had to go away for work – was a problem for many ARV users (34% in the non-adherence and 11% in the optimum adherence groups) – probably because they found it hard to negotiate more than one month's prescription of ARVs at a time or because they had to go on work excursions on short notice. Some ARV users in the non-adherence group (26%) further found it very hard to negotiate time off from work to get prescriptions filled (also cf. Tosolari, 2009) mainly because they did not want to disclose their ARV-taking behaviour to employers out of fear of discrimination.

Forgetting to take their ARVs during weekends was also a big problem for 22% of those who defaulted on treatment, while others openly admitted that they refuse to take their ARVs over weekends because, as one participant put it: "it is seriously bad for my social and sexual life to take ARVs all time. Weekends I party, so I don't take my ARVs." These "treatment holidays" during weekends can easily amount to a treatment interruption of 48 to 60 hours at a time – enough time for HIV drug resistance to develop with certain regimes. In contrast, only 1.1% of ARV users in the optimum adherence group forgot or deliberately did not take their medication over weekends (1.1%).

Of interest was the finding that there was no correlation between adherence and the use of reminders (like cell phones and singing or dancing pill boxes) or the number of such reminders being used (also cf. Wessels, Nattrass&Rivett, 2007; Wise &Operario, 2008).

ARV users in the non-adherence group found it particularly hard to communicate certain problems to healthcare workers, for example regarding emergency hospitalisation without their ARVs, and shortages – they would rather discontinue or skip ARV dosages when experiencing side effects, than to communicate this to healthcare workers. ARV users in the adherence group had less difficulty in communicating their problems to healthcare workers, and they asked for healthcare advice, treatment, or a change in regimen when necessary.

Some of these issues could be addressed by teaching ARV users particular skills, such as communication and negotiation skills; self-efficacy; and ARV management and planning skills. Adherence counselling should further not be seen as a once-off event. Regular re-counselling to address problems and to counter treatment fatigue is extremely important.

ARV literacy or knowledge

Knowledge and a clear understanding of their ARV treatment and the importance of adherence, contributed significantly to adherence in the study. ARV users were generally well informed about the importance of ARV adherence, but many did not understand the relationship between non-adherence, drug resistance and drug failure. In the non-adherence group, 30% did not know that non-adherence can lead to drug resistance and failure; 43% did not realise that drug-resistant viruses could be passed on to a sex partner, and 60% wondered what all the fuss was about, because – should drug resistance develop, the clinic could *"simply prescribe another drug that works."* (Also cf. Skhosana*et al*., 2006; Aspeling& Van Wyk, 2008; Kip *et al*., 2009).

This result shows that knowledge as a determinant of ARV adherence should not be neglected in behaviour change models. Continued patient education (individual and in groups) should therefore form a crucial part of ARV-adherence counselling

Perception of lack of control over own health

Perceptions that they don't have control over their own health, and that nothing they do will make any difference to their situation, also predicted ARV non-adherence in the study. Forty four percent in the non-adherence group believed that what happens to them is destined by factors outside their control. Some of the reasons given for not being in control of their health were the following:

- the nature of the illness, which is often unpredictable;
- living in disempowered communities – especially women who felt that their health is not in their own hands but in the hands of powerful others like sex partners; and
- cultural beliefs. Some participants in the study believed that Aids was sent to them by jealous neighbours, or that they were bewitched, and that they didn't think the ARV would really help them.

Stigma and discrimination as a barrier to adherence

The final barrier to ARV adherence that I want to discuss is stigma. Stigma, discrimination and the lack of social support are often mentioned in the literature as some of the main reasons why ARV users hide their HIV status, as well as their ARV taking from colleagues, friends and others (cf. Skhosana*et al*., 2006; Hardon*et al*., 2007; Aspeling& Van Wyk, 2008; Dlamini*et al*., 2009; Kip *et al*., 2009; Nachega, 2009; Tosolari, 2009).

Seventy five percent of ARV users (from both groups in my study) said that stigmatisation was still rife in their communities and that a culture of non-disclosure still existed. Sixty percent mentioned times in the past when they had to hide the fact that they were on ARVs due to their communities

not being “open” to HIV and ARVs. A third in the non-adherence group often skipped their ARVs because they did not want people close to them to know that they were HIV-infected. This statistic is compared to 7% in the optimum adherence group who sometimes skipped dosages for this reason.

Although both groups experienced stigma and discrimination, there was a difference in the way they perceived and coped with them. For the adherence group, stigma was often an “impersonal” annoyance which they could ignore. In contrast, stigma took on a very personal note in the non-adherence group where it was associated with secrecy, fear, and lies. Participants told stories about being part of big families and how they always have to look for a private place to take ARVs; others have to take the pills out of the original package and lie to their families about what medication they are taking or hide their pills in a neighbour’s house. A young woman who lives with her parents who don’t believe that there is such a thing as the HI virus explained: “How can I tell them that I have AIDS and that I am taking these pills? It will kill them, but the secrecy is killing me.’’

Some, especially women, kept their HIV status as well as their ARV-taking behaviour a total secret from their sex partners. Of those who kept it a secret from their sex partners, only 21% could reach optimum adherence levels. Fear of blame, rejection, losing their children, violence and even being killed were some of the reasons given by participants for their silence.

Stigma and the fear of discrimination were also the main reasons (given by both groups) why 43% did not keep treatment records; why 31% did not belong to support groups; and why 26% said that they do not have treatment supporters. “If I keep a record, people will find it, and I will be finished.” “Support groups are dangerous because people will think that you are up to no good.” “They will get suspicious and accuse us of witchcraft.”

The requirement (or the perceived requirement) that people will only be accepted into a treatment programme if they disclose their status to a friend or a family member who will support them is a barrier to many people in Africa to take up ARV treatment. In his research on ARV support groups in Venda in 2009, McNeill was struck by the public silence surrounding health, sickness and death. This public silence, according to McNeill, should not be seen as a lack of knowledge or as denial, but as an act of self-defence against stigma. Aids is associated with death and in many African cultures death is not seen as a natural occurrence. Untimely death and serious diseases are often ascribed to witches, spirits or people with ill intentions. Knowing too much about death and Aids generates suspicion in other community members about one’s own involvement in sickness and

death.

McNeill further found that members of ARV support groups (all women) practised highly selective disclosure because they feared for their lives should it become general knowledge in their communities that they are HIV-infected (McNeill, 2009). The women were also highly secretive of their activities in the group and they went to great lengths to maintain this strict code of secrecy. But in reaction to this, some people in surrounding villages became suspicious and accused the women of being witches or zombies. “For how else could they have made the transition from near death to full health and productivity?” they asked (McNeill, 2009: 99). An HIV support group’s survival thus depends on its ability to remain shrouded in total secrecy. Although I focussed on McNeill’s Venda’s study, it should be noted that this need for secrecy also occurs in more Westernised cultures and communities.

But where does this leave the healthcare worker in Africa? Stigma as a barrier to ARV adherence should be seriously addressed, and skills to cope with stigma and discrimination should be facilitated in ARV users. This must also include the skill to adhere in the midst of silence and secrecy. National guidelines on disclosure should further be applied in a pragmatic manner, suited to the cultural context in which ARV users live.

Intervention plans will not be successful if stigma, discrimination and violations of human rights are not directly addressed at a higher structural level. Structural interventions in the form of policy, legislation and provision of services are necessary where social, political and economic structures make people vulnerable to HIV infection and restrict their access to prevention, treatment and care. Everything that we win in terms of behavioural and bio-medical interventions might be lost if violation of human rights prevents those most in need of ARVs from accessing them and from adhering to them.

CONCLUSION

Antiretroviral drugs are indeed “wonder-drugs” that can save millions of lives. But do we use these wonder-drugs wisely, or are we burning one of our last bridges to stop this epidemic? The overall picture that emerged from my ARV adherence study and the literature in general, is alarming and we might face a huge health crisis in future if we do not take steps now to address adherence barriers and increase adherence levels. Early detection of non-adherence and prompt intervention can greatly reduce the development of viral resistance, and the likelihood of treatment failure (NIH,

2011). "Access-to-all" campaigns are no longer acceptable without adding the important "Adherence-by-all" message.

The support of people on ARVs can however not only be the responsibility of the state and the healthcare system. HIV drug resistance poses a problem to every one of us who does not want to return to the dark pre-ARV era when people died in their thousands. It therefore becomes a community obligation (including academic institutions, church organisations and workplaces) to support ARV users to overcome their barriers and to manage their own health by adhering to their ARVs.

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