"They (ARVs) are my life, without them I’m nothing"—experiences of patients attending a HIV/AIDS clinic in Johannesburg, South Africa

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ABSTRACT

This paper is a part of a larger study that explores the “social complexity” of antiretroviral therapy (ART), in resource-limited environments. Drawing on in-depth interviews with a sample of 44 patients in an urban HIV/AIDS clinic in Johannesburg, South Africa, this paper examines how people with HIV/AIDS conceptualise their illness and its treatment in this context. The paper concludes that the fear of stigma plays a significant role in patients’ experiences throughout the disease trajectory. Yet, demonstrates that there are indications that ARVs are transforming the experience of living with HIV/AIDS and a process of normalisation is taking place. Despite the resource-limited context and, often, lack of family and community support, patients see the ARVs as ‘life saving’ and express their long-term commitment to adhere to the drug regimen as well as their trust in health professionals.

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1. Introduction

It is now widely accepted that effective available medical technologies such as antiretroviral drugs have transformed HIV/AIDS from an acute life threatening condition to an established chronic disorder within a list of other such conditions that can be effectively managed (Persson et al., 2003; Pierret, 2007). This has resulted in a shift in emphasis from preparing people to die, to prepare them to live with the virus, the drugs and the required life-style changes (Westburg and Guindon, 2004; Wong and Ussher, 2008). There have been accounts of people who have been brought back from near-death (Persson, 2004; Robins, 2006) and given a ‘second life’ (Rabkin and Ferrando, 1997). Surviving HIV/AIDS is now not only possible but highly probable for people living in resource-rich countries (Persson et al., 2003). Unfortunately, this is not the case in resource-limited countries where the available medical technology can be accessed only by a fortunate minority due to unavailable or limited resources (Cameron, 2005; UNAIDS, 2008; Langa, 2009; Thom, 2009; Heywood, 2009). This renders the concept of ‘life-saving’ therapy, both more meaningful and tenuous (Thom and Langa, 2009).

Adherence to ART in South Africa is significantly influenced by the social, historical, cultural and geographical context of HIV/AIDS. Marks (2008) argues that AIDS was an epidemic waiting to happen; the regions’ complex social history has compounded the way in which the epidemic has unfolded over the past three decades. Southern Africa has a long history of forced population
migration, which has resulted in large-scale family disintegration and dislocation. The region has also been racked by social conflict and wars. Furthermore, the ongoing epidemic of tuberculosis (TB) in South Africa has been directly implicated in the AIDS epidemic in a number of ways, with TB substantially increasing the number of AIDS-related deaths (Walker et al., 2004). According to the World Health Organization’s Global TB Report 2008, South Africa had nearly 453,929 new TB cases in 2006 with an incidence rate of an estimated 940 cases per 100,000 population—a major increase from 338 per 100,000 population in 1998. The TB–HIV/AIDS co-infection rate is high, with 44% of new TB patients testing positive for HIV (USAID, 2009). Health and health care during the apartheid era have left a legacy of inadequate facilities and a health care system built on a public–private divide which remains fundamentally unequal. Gilbert and Walker (2002) demonstrate that HIV/AIDS in South Africa reflects both historical and ongoing social inequalities of race, class, gender and place—this is confirmed by more recent studies. The latest HSRC national study (Shisana et al., 2005) found that race, gender and place of residence continue to determine the prevalence rates while the latest differential prevalence rates between the provinces, which vary in their racial and urban/rural mix as well as economic resources, add credence to the above (DOH, 2008). It is South Africa’s resource-limited environment which has shaped the epidemiology of the epidemic historically and continues to influence the experience and meaning of ART for PLWHA.

Although accurate data about the number of people in need of treatment in South Africa are not available, estimates are that 5.7 million people are already infected with HIV and will eventually be in need of treatment (UNAIDS, 2008). Following a troubled period in which the government failed to come up with an appropriate treatment plan, as alluded to earlier, which was accompanied by wide-scale controversy and active campaigning within civil society, the government announced a gradual ART roll-out in 2003 (DOH, 2003; Natrass, 2007). The provision of ART also followed a landmark decision by the South African Constitutional Court in 2002. In a case where the Treatment Action Campaign (TAC) challenged the Minister of Health, the Court ruled that the State had a duty to provide the drug Nevirapine to HIV-positive pregnant mothers to reduce the risk of mother-to-child transmission of HIV. Despite the initial slow progress of the ART roll-out, there were 411,889 people on ARVs by 2008 (JournAIDS, 2008).

The South African government’s decision to introduce ART programmes (Natrass, 2007) has provided a welcome relief from its long-standing indecisiveness on this issue as well as an indication of its commitment to stemming the epidemic. At the same time, however, there is no doubt that successful implementation is costly and “socially complex” (Benatar, 2004). There are many difficulties associated with the provision of ART to hundreds of thousands of people, in addition to offering integrated care for other associated diseases of poverty (DOH, 2007). It presents major challenges in terms of cost, health care delivery and a range of other social and cultural factors (Farmer et al., 2001; Murray et al., 2009). Although, there is a large body of research exploring issues related to ART, much of this literature focuses on populations in well-resourced countries emphasising the medical aspects associated with adherence to therapeutic regimens such as side effects (Mykhalovskiy et al., 2004). Despite a widespread recognition that understanding ART needs to extend beyond the medical model (Persson et al., 2003), there are not enough qualitative studies focusing on the psycho-social and cultural aspects. The paucity of qualitative studies that offer a more nuanced understanding of the disease and treatment from the patients’ perspective is particularly evident in poorly resourced countries (Farmer et al., 2001; Skhosana et al., 2006; Murray et al., 2009).

Following a long tradition of research exploring lay understandings about treatment (Britten, 2008), there is now a growing body of research exploring social differences in relation to health and bodily practices and the management of chronic illness (Horne et al., 2004). In the case of HIV/AIDS, there is evidence to suggest that long-term success of ART programmes will be determined by a better understanding of the wider social, geographical and cultural context (Gill et al., 2005; Murray et al., 2009). This is important in any multicultural society, however, in South Africa it acquires particular significance as the HIV/AIDS epidemic has been framed within ‘racial and ethnic’ dimensions (De Vos and Baim-Lance, 2002).

This paper aims to provide insight into the social complexities associated with the provision of ART in a resource-limited setting in an urban clinic in South Africa with its unique socio-political history. In particular, we explore how people with HIV conceptualise their illness and how they experience the full trajectory of the disease from testing and disclosure, to treatment. In doing this we aim to provide a wider perspective beyond the often, narrow reductionist medical framework employed by the compliance or adherence model of health care interactions (Bissell et al., 2004).

2. Methodology

The study took place in a public sector HIV/AIDS clinic in a decaying, inner-city suburb of Johannesburg, South Africa. Although administratively this clinic is a part of a Community Primary Health Centre, it is physically removed and separated from the rest of the centre. It is located some distance away in a renovated section of an otherwise unused, dilapidated hospital. The clinic started a roll-out of ARVs in October 2004 following a long and protracted struggle for wide-scale provision of ARVs in the context of the government’s refusal to provide the necessary treatment (Butler, 2005; Natrass, 2007).

This is a qualitative study based on data collected by means of in-depth face-to-face interviews with a randomly selected sample of 44 patients who attended the ARV clinic. The field work took place between June and November 2007. Due to technical difficulties in obtaining an accurate list of patients on ARVs, respondents were selected on the day of the interview when sitting in the clinic’s waiting room. The choice was made randomly counting all patients at the time.

Patients were approached for interview by two interviewers who could communicate in an indigenous language if needed. The interviews were conducted by research assistants who were specifically trained by the principal investigator in order to achieve inter-reviewer reliability. Once the selected patients confirmed their availability, the aim of the study and purpose of the interview were clearly explained and written or verbal consent obtained. Since the lack of intake of treatment by men is a well-recognised problem in South Africa, we purposefully sought additional men for the interviews, but only succeeded in recruiting 12 men.

The interviews were conducted in one of the consulting rooms in the clinic, creating a private space to facilitate an open and confidential encounter. They lasted approximately an hour. The interviews were semi-structured using an interview schedule as a guide only with the view of getting a ‘rich’ and detailed account of the subjects’ understandings, feelings and experiences (Yates, 2004). Although, the interview focussed on the patients’ career path and experience with testing, diagnosis, help-seeking and treatment, the interviewers were trained to probe beyond that and encourage patients to talk openly about their lives with HIV/AIDS. The interviews were later transcribed and their content was
coded and analysed (Mason, 1996; Coffey and Atkinson, 1996). The two researchers independently identified core themes. The approach to the data analysis was based on the grounded theory approach where we sought to locate our conceptualisation and theorisation in the interview data rather than pre-existing hypotheses (Yates, 2004).

As a part of the larger study, we also interviewed health workers in the clinic. Although this paper does not focus on them, we have incorporated some comments made by them to illustrate a point when appropriate.

Ethics approval for the study was obtained from the Human Research Ethics Committee (Medical), University of the Witwatersrand, Protocol no. M070537.

3. Analysis of findings

Patients ranged in age from 16 to 59, of whom the majority (32) were women. Nattrass (2008) argues that women in South Africa access ART in disproportionately large numbers and suggests that the ‘masculinity factor’ is one reason for this. As with other help-seeking behaviours, men are reluctant to come forward for treatment and are less likely to disclose their HIV positive status. Adamson et al. (2007) also argue that the higher numbers of women on ART is due to their contact with antinatal clinics and that men are more likely to access treatment much later. Their educational level varied from low primary school grades to post-matric diplomas. This was reflected in their various occupations such as domestic workers, sales consultants, construction and security employees. Fifty percent of the respondents were unemployed and 20% worked as part-time. Most patients came from areas outside the clinic and far away from Johannesburg. It is of importance to note that most had access to ART in the areas they came from, but chose to come to this clinic in order to maintain anonymity and avoid stigmatisation.

The starting point for this research was to understand the ‘HIV/AIDS’ journey’s respondents (who have been on treatment for some time) had travelled prior to their arrival at the clinic—for most their journeys commenced with testing.

3.1. Testing HIV positive

Many studies (Deacon, 2005; Steinberg, 2008) suggest that one of the main barriers to early testing is the fear of stigma. This is evident in this study. Most interviewees mentioned specific circumstantial triggers for testing such as pregnancy, death of a partner, employer’s insistence and others. Although they had their suspicions, they avoided being tested since they were fearful of a HIV positive diagnosis. National prevention campaigns in South Africa encourage men and women to know their HIV status to prevent further infection and access early intervention. Health policy which encourages early (and regular) testing is designed to create a ‘spirit of openness’ around HIV/AIDS and confront stigma. We found no evidence that the testing was done in the spirit of ‘doing the right thing to know your status’ as highlighted in most educational initiatives (Campbell and Williams, 1999; Collinge, 2005). Instead, scrutiny of the circumstances around the testing clearly indicated that in all (but one) cases there were unique final triggers that, as respondents said, ‘forced’ them to ‘take the plunge’ and submit to testing (Gilbert and Walker, 2009, in press).

One respondent commented,

My boyfriend told me that he was HIV positive in December 1998. He encouraged me to go and test, however I was afraid as I was pregnant with his child and I knew that he must have infected me, but later on I gave in and went to test with him… Another said,

I found out about my status after my accident when I was admitted in hospital, they tested my blood without my permission and told me my status when I was supposed to be discharged. The doctor told me my status.

For these respondents, their HIV positive status was thrust upon them by outside forces and agents, sometimes unexpectedly and unknowingly, compounding their anxiety and fear.

3.2. Disclosure

Much has been written about the benefits of public disclosure for people who are HIV positive—this has accompanied the early campaigns for ‘coming out in public’ (Shisana et al., 2005). However, the decision to disclose is generally a difficult and complex process. People living with HIV/AIDS (PLWHA) are confronted by many factors that strongly discourage both public and private disclosure such as moral judgment and blame; ostracism by household or community; relationship termination; verbal and/or physical abuse and discrimination.

The interviewees in this study describe experiences of stigma and rejection. This research indicates that once HIV positive status is revealed, there is usually some support from the immediate family such as their mother and/or husband. However, fear is often the main factor behind a deep reluctance to disclose to other family members, employers and sexual partners. Some respondents commented as follows:

I did not tell my husband as he had previously revealed that he would kill me and the child if he knew we were HIV positive. This made me feel bad and keep our status a secret.

It was not easy to disclose my results to my employer, I was scared, I didn’t know my employer knew all these years… . I was so scared to tell her.

Respondents in this study relied very heavily on the clinic and the health workers from whom they received welcome support and understanding as they had nothing to hide from them.

A Primary Health Clinician interviewed in this study argued that disclosure is the biggest challenge in “getting patients to stick to treatment”. More specifically, she said:

Disclosure is a big issue for patients. Especially for those with partners and families and those who are employed. If they don’t disclose then the many questions from employers and/or partners put them off from coming back to the clinic for treatment.

Popular perceptions of AIDS are undoubtedly shaped by a wide variety of factors including the contextual nature of AIDS-related stigma in different communities, people’s understanding of the source of illness and misfortune, the availability of life-prolonging ARVs and people’s exposure to ‘treatment literacy’ initiatives. The decision to disclose HIV status to others occurs within this framework, and in turn, reshapes them as people respond to the person who has just disclosed (Almeleh, 2006). The findings of this study underscore the complexity of disclosure and the ways which stigma impedes and sometimes prevents disclosure. The inability and reluctance to disclose HIV/AIDS status impacts on all dimensions of the illness, including where and how to seek help, and how to incorporate a highly complex treatment regimen into daily life.
3.3. Living with HIV/AIDS

At a time when the biomedical model is the dominant discourse within medical systems and the emphasis is on ‘evidence-based’ practice, analysts have expressed the concern that the ‘patient’s view’ is likely to be downplayed in favour of scientifically and statistically orientated ‘evidence’ (Gabe et al., 2004). Yet attention to ‘illness narratives’ that reflect the patients’ experiences and the meanings they attach to symptoms as well as to the drugs are as important as ‘evidence-based’ guidelines (Greenhalgh and Hurvitz, 1999). Accordingly, the illness experience, particularly in relation to chronic conditions, as expressed through the patients’ illness narratives is as important to the patients’ ‘making sense of the disease’ as well as to the practical management of such disorders (Pierret, 2003).

This is particularly true in the case of HIV/AIDS (Pierret, 2007) where the biomedical model fails to provide answers to many aspects of the disease and its treatment in various cultural contexts. For this reason, the use of ‘illness narratives’ has been adopted in this study in order to elicit key dimensions of the experience of HIV/AIDS and its various meanings (Bury, 2001). The paper now turns its attention to key elements of the illness experience: a journey that for many respondents begins with making sense of the virus, and includes the challenges of taking and managing ARVs.

3.3.1. Relationship with the virus

It seems that an integral component of the HIV/AIDS illness experience is the need to develop a relationship with the virus. Interviewees spoke of positive relationships with the virus, which included communicating with it as an external, self-contained entity. This appeared to counter or at least contain some of the negative, health and social effects of the virus. It also made it less diffuse: the virus became something tangible, real and specific. This is particularly interesting in relation to HIV which is notoriously elusive, and in the South African context, characterised by myth, cultural curiosity, skepticism and denialism.

Respondents commented positively,

The virus is now my friend. I call the virus George. I speak to him, I tell him I need to work...

I speak to this HIV and tell it, hey you, you have no power over me I am a strong black woman and my life is in God’s hands not yours

Some had a more ‘adversarial relationship’,

I would like to see this virus and this might give me clarity on how this virus that is assumedly so tiny can cause such havoc in my life.

One respondent spoke of his fear of the virus and its power to make him dangerous to others:

I’m very scared of having sex or being intimate with another woman. In fact I have not been with a woman since my woman passed away. I’m scared that I’ll infect the next person.

For these respondents, the virus is a part of the body, and of life which requires cajoling, nurturing, reprimanding and for all respondents, controlling.

3.3.2. Perceptions of ARVs

There is no doubt that the patients in this clinic see the ARVs as their life-line. The ARVs are the means by which they survive. They represent the possibilities of health and the future. Yet, they also represent dependence and fear, for without them (and the possibility of their withdrawal) illness would prevail. As two respondents commented,

They (ARVs) are my life, without them I’m nothing.

These pills have given me a new lease on life. I no longer have sores, cough and the constant feeling of exhaustion is gone.

The quotes above echo findings from other studies where adherence was attributed to the dramatic reverse of health status as a result of the treatment (Cameron, 2005; Skhosana et al., 2006).

Another respondent expresses these sentiments and also signals an underlying fear of the potential withdrawal of access to the ARVs.

These pills mean life to me, so if they were no longer accessible I would die.

These fears reflect the context of general competing demands for health resources in South Africa and frequent media coverage of shortages of ARVs (Thom and Langa, 2009; Heywood, 2009).

3.3.3. Normalisation

The provision of ARVs makes life possible but it also profoundly changes the nature and experience of the illness (Pierret, 2007). Respondents spoke of feeling better, of looking better, of looking ‘normal’. The data suggest that a ‘process of normalisation’ is taking place, as in cases of other established chronic conditions, such as, rheumatoid arthritis, diabetes or hypertension (Bury, 1999; Pierret, 2003). For example:

I’m not scared of taking tablets and there are no feelings attached to this medication. I treat them as contraceptives.

I know that these pills are my ticket to health and a normal life. Taking the medication becomes your life-style.

These quotes also illustrate the positive effects of ART and their influence on the wider community. A primary health clinician said,

now that people see others get well—more come to the clinic.

This is corroborated by the rapid increase in the numbers of people approaching the clinic for help.

Ashfort and Nattrass (2005, p. 292) observe that having AIDS is “tantamount to saying a person is already dead”. They maintain that “insofar, and for as long, as treatment is successful the patient will seem healthy and the risk of pollution to others from contact with those ‘already dead’ will diminish along with the ‘stigma’ related to this”. Therefore, if the process towards normalisation continues and gathers momentum it has the potential to reduce the stigma associated with HIV/AIDS and its negative effects.

Similarly Castro and Farmer (2005) argue that access to ART triggers a ‘virtuous social cycle’ by alleviating visible signs of disease, facilitating a return to a productive social life (Mahajan et al., 2008), further normalising the experience of living with HIV/AIDS.

Coupled with the ‘gratitude’ expressed towards ARVs, respondents also spoke of the burden of the virus and the ‘load’ of medication of never being able to escape the virus. For many interviewees, this was compounded by the very public nature of HIV/AIDS in South Africa—high profile prevention and intervention campaigns, which dominate public life and constantly ‘remind them’ about their condition.

3.3.4. Managing treatment and complex drug regimens

Patients attending this clinic have been given counselling and explanations about the drug regimen, expected side effects, handling stress, improving nutrition and adjusting their
life-styles. Every day there is a talk by the doctor or another health worker in addition to private consultations. Thus, patients become very familiar with the language of HIV/AIDS, including their drugs. Indeed pharmaceutical knowledge and terminology related to AIDS have saturated South African public life in general. Previously highly specialised knowledge has become ‘popularised’—and HIV/AIDS-related terminology is now used by ‘laymen’—CD4 count; viral load, antibodies and antiretrovirals have all become commonly incorporated into everyday conversation.

Although the terminology is widely used, there is no guarantee that its meaning is clear. In fact, often, it is not well understood. This is of particular concern when more difficult cases are presented, for example,

My sister has had side effects from the pills that they are giving out at this clinic…. I would like to know why this treatment has made my daughter sick and even resulted in her constant loss of weight, while it has not had the same effect on me.

Like the virus, side effects are sometimes difficult to understand because they vary from one person to another. The above example illustrates the complexity of the treatment as well as the need for the patients to have a good level of understanding, which is often difficult to achieve despite the efforts of health workers.

Respondents commented on the challenges of taking the ARVs, for example, the side effects and the quantity of drugs they are required to take.

Respondents commented thus,

Too many pills—why can’t we just drink one pill a day or get an injection once a month?

My issues about these drugs are that they make me feel dizzy and feel sleepy, so this becomes a problem at work sometimes. It is frustrating to take medication, but it helps… but till when?

Will I take them until I die? What else can I do?

The interviewees talk simultaneously of the life-giving possibilities of ARVs and their dependence on them, yet identify the burden they represent—the burden of side effects, of complexity, and the fact that they are forever: there is no escape from a life on ARVs.

3.3.5. Adherence to ARVs

Despite the difficulties attached to taking ARVs, respondents signalled their willingness to adhere to the medication. They identified a number of factors, which facilitated this: the nature and the context of disclosure, support of their partners, employers and families, and all of them used technology such as mobile phones to assist with their routines. And, as with other conditions, respondents noted that when they feel better, they are less likely to comply.

Their children were a very strong motivating factor in sticking to the regime, in supporting their efforts to adhere to the medication, as evident in the following comments:

I was feeling very stressed and thought of killing myself but I had to think about my children and be strong. I’m happy taking the medication as long as it helps me—I want to see my kids grow up.

“What example would I set for my daughter” … if I die what will happen to my children?

Similarly support from employers facilitated their adherence:

I feel fine and manage to take my medication. I have a pills tray from my employer. The family I work for helps remind me. My employer buys me veggies and encourages me and reminds me about my clinic visits. It has been important to have my employer. It has taken away the negative thinking and improved my health.

Partners and families were also central in supporting respondents with their drug regimes and many played a positive role:

I revealed my status to my partner; … my partner helped me through this difficult time, we became highly dependent on each other as we are both HIV+ and thanks to the medication the children are HIV negative.

This respondent who has only revealed his HIV+ status to his wife said:

I believe support is vital, my wife is helping me a lot, and she takes care of me in every way and makes the right food for me which helps me focus on life and gives me energy.

Conversely, a lack of support from partners has been identified as a barrier:

I set a reminder on my cell phone; however, my partner is starting to question why I have to take medication every day. He has even suggested that I might be HIV+ when we fight… taking the medication has become hard, as he has started questioning my need for medication…

My partner… after a while he left me for another woman… this hurt me and I became very sick, my CD4 count dropped and I was extremely stressed.

Some families provide extensive support, yet many respondents spoke of their families’ rejection and some had not revealed their status to them for fear of their response.

All my family know my status… families don’t treat you well. They won’t share spoons, bathroom etc… they watch you closely… nobody wants to come to you when you are ill, especially my mother—they avoid you. They make harsh judgements about you, like when someone is naughty or bad, they say ‘don’t be like this or else you will end up like her…’—this is hurtful. They also exclude my kids even though they are negative”.

These respondents are managing the effects of stigmatisation and stigma by association (Walker, 2007). This follows other studies which point out that isolation of entire families and specifically rejection of children is not uncommon (Madhavan and Townsend, 2007; Deacon and Stephney, 2007).

In the context of stigmatisation, many respondents spoke of a need to find a safe space, a heaven where they were supported and where they did not need to hide their condition or their medication, thus facilitating their continued adherence to the medication. Many spoke of finding this in the clinic. In contrast to the well-researched judgemental attitudes of nurses (Walker and Gilson, 2004), respondents spoke of their positive experiences.

In a comment which echoed many, one respondent said:

The staff and doctors are able to listen to problems. I am used to them, and they are used to me. It feels like home here. They call you to check if you don’t come on your day. That makes me feel they are concerned – they remind me – I like this. I also like to talk freely with patients at this clinic.

It seems that this respondent’s experience is shared by other interviewees and observed by the researchers in the clinic. Arguably, there is a “development of clinic culture” among long-term patients and staff where patients are drawing on resources from each other.
4. Discussion and conclusion

This research highlights the multiple complexities of living with and managing HIV/AIDS treatment in South Africa. It points to the contradictory relationships which PLWHA develop with the virus and their need to externalise it in order to live with it and ultimately take control over it. In southern Africa the virus has long been regarded as enigmatic, difficult to explain and imbued with cultural meaning. This remains the case in the context of treatment where the effects of ARVs and their management differ markedly (Ashfort and Nattrass, 2005). Yet, in the context of this urban resource-limited clinic, patients have embraced their treatment. We have noticed that ARVs are transforming the experience of living with HIV/AIDS for many respondents. Although based on research in one urban clinic, the data in this study indicate some shifts towards understanding, living and managing HIV/AIDS in a similar manner to other chronic conditions. Thus, confirming our earlier suggestion that comprehensive provision of ARVs is likely to contribute to the move away from AIDS in South Africa automatically meaning 'AIDS' doesn't work in Africa because many Africans don't use clocks and 'don't know what western time is' (McNeil, 2003). Prior to the more widespread provision of ART in some clinics in South Africa, many argued that because of the social, cultural and medical complexity of ARVs, it simply would not work. This research cautiously challenges these original conceptions. For the selected group of people who participated in this study, it can be said that although stigma permeates their lives, the positive effects of ART and their ability to adjust their lives to accommodate it, are shifting their perceptions about and experiences of HIV/AIDS. Despite the negative climate there is a feeling that due to the privileged access and the hope of a better, 'normal' life, it is worth the struggle.

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