

Medicines of Hope?

The Tough Decision for Antiretroviral Use for HIV in Zanzibar, Tanzania

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Abstract

The provision of free antiretroviral treatment for AIDS in Zanzibar since March 2005 is the result of enormous struggles at a global scale and has provided immense relief for sufferers. At the same time, the new ‘medicines of hope’, as they quickly became known, have produced new uncertainties about how best to respond to HIV/AIDS, both for the infected individual and for the society at large. ART programmes make possible a biologised, pharmaceutical life. Drawing on three case studies this paper shows how HIV-positive people struggle to make decisions in an environment characterised by deep uncertainties about the nature and causes of HIV/AIDS in particular, and about the continuity of Zanzibari society in general. It argues that health interventions cannot be orientated to ‘life itself’; they must be attuned to the contexts in which life takes place. Analysing people’s actions and behaviours in the context of their lives-as-lived throws light onto apparently irrational decisions and emphasises the importance of an in-depth understanding of local moral worlds and social contexts.

Keywords: HIV/AIDS, Zanzibar, antiretroviral treatment, uncertainty, morality, life itself

Introduction

Responding to intense activist mobilisation, the past decade has seen a significant turn in the global response to HIV/AIDS: while in the 1980s and 90s approaches to HIV/AIDS in low-income countries had strongly focussed on prevention, and antiretroviral treatment (ART) was regarded as economically and logistically unfeasible, by the early 2000s intense activism had succeeded in redefining treatment access as being a moral imperative and a public health necessity.¹ As a result, in December 2001, UNAIDS for the first time publicly announced its support for antiretroviral treatment for all in need. Generic drug production had radically lowered the cost of treatment, and new funding instruments were created in a concerted effort to roll out free antiretroviral treatment of AIDS in the global South.

Over the first decade of the 21st century, resources made available for antiretrovirals (ARVs) have vastly expanded, and funding streams rapidly shifted from prevention towards treatment since the first mass ART programmes were started. By the end of 2011, approximately eight million people were on antiretroviral treatment,ⁱⁱ out of an estimated 14,8 million in immediate need. However, the epidemic continues to be outpaced by the rate of new infections, and funding for AIDS interventions has started to flat-line. As the sustainability of widespread long-term treatment becomes increasingly questionable, new solutions are called for, and recent debates about ‘treatment as prevention’ have demonstrated growing enthusiasm for finding a pharmaceutical solution for AIDS, both through renewed commitment to finding a cure for AIDSⁱⁱⁱ and through intensifying treatment coverage and the more strategic use of ART,

including the prophylactic treatment of HIV-negative people classified as being at high risk of becoming infected.^{iv}

This shift from prevention and clinical care towards an increasing emphasis on access to drugs is indicative of a broader trend towards a pharmaceuticalisation in the realm of public health.^v But while antiretrovirals may first have appeared as magic bullets in the fight against AIDS, recent studies on ART^{vi} and on other mass drug administration programmes^{vii} have demonstrated manifold problems with access, adherence, and monitoring and evaluation of such programmes. Allen and Parker^{viii} in their analysis of widely varying rates of treatment uptake for neglected tropical diseases (NTDs) point to the importance of differences in socio-economic contexts and highlight patients' concerns about side effects, the rationale for treatment (particularly in the absence of symptoms), and barriers to drug access due to implementation design. Many of these concerns resemble those encountered in the treatment of AIDS.

At the same time, antiretroviral treatment poses additional problems, due to its long-term nature and the importance of adherence to a strict treatment regimen. For the first time, large-scale, complex, lifelong treatment for the management of a chronic disease has been implemented in low-income countries, and many of the issues that arise are comparable to those known from the management of chronic conditions elsewhere, including the difficulty of adjusting life to the treatment regimen, treatment fatigue, the ambiguity of people who are sick but fit at the same time, and their constant uncertainty about what they are capable of in the face of the ebbing and surging of symptoms and side effects. Moreover, biomedical management of chronic conditions creates tensions between individuality and sociality:^{ix} medication and recommendations about healthy lifestyles focus on the individual and tend to overlook the difficulty of making special arrangements for one household member, especially in the presence of poverty and generally high levels of ill health, as experienced by many of my informants. These issues highlight the embeddedness of treatment uptake and outcomes in social processes and the need for strong social support in the management of long-term conditions.

Yet, treatment programmes that focus predominantly on drug access rely heavily on the construction of an individual self who is responsible for their own health and promote a notion of life that is chiefly biological, concerned with physical survival, or 'life itself'^x above all else. This contrasts sharply with my informants' views on the treatment. While obviously concerned about survival, they emphasise their social and moral personae whose actions and experiences are profoundly impacted upon by their social contexts and local moral worlds. Their notion of life is one more akin to what Fassin has called 'life as such': 'the course of events which occurs from birth to death, which can be shortened by political or structural violence, which can be prolonged by health and social policies, which give place to cultural interpretations and moral decisions, which may be told or written – life which is lived through a body (not only through cells) and as a society (not only as species).'^{xi} Such life-as-it-is-lived is a dynamic process, rather than a biological given, operated through discourses, programmes, decisions and actions which invoke and rework a situated form of moral reasoning in order to provide a possible guide to action.^{xii}

Antiretroviral treatment

The struggle for access to antiretroviral treatment in low-income countries has been long and arduous, and is far from over. Debates ranged from economic feasibility to patent issues, generic drug production and quality control, and the problems of ensuring treatment adherence

and widespread access in areas that lacked infrastructure, qualified personnel, and storage and distribution facilities. Throughout, it was assumed that demand was not going to be a problem. On the contrary, it was feared that demand would be so high that already overburdened health care centres would not be able to cope with the wave of people in need for treatment. And indeed, in many places exactly this happened. In the early days of treatment rollout, for example, clinics in Dar es Salaam had to decline new patients, and since 2010 drug shortages were reported in several sub-Saharan African countries.

When free ART was introduced in Zanzibar, a small island archipelago off the Tanzanian coast, in March 2005, it met a population that was largely ‘treatment-naïve’: within weeks, HIV-positive people went from the occasional provision with paracetamol and anti-fungal creams to access to state-of-the-art medication that most had not even known existed. It was a historic point in time that would shape HIV-positive people’s lives significantly: the ‘drugs of hope’, as they quickly became known in Zanzibar, would bring back to life those who were almost dead and offer the prospect of a future as ‘normal’, productive and reproductive members of society. And yet, the intense excitement that one may have expected was lacking. Overall the treatment programme here has been successful, and members of ZAPHA+, the island’s only support group for HIV-positive people, were excited about the prospect of treatment becoming available. However, when talking to my informants individually, I found that many were cautious about coming forward for treatment and were carefully weighing their options.

From the perspective of public health experts and medical doctors, treatment literacy – defined as ‘the capacity to interpret information about HIV/AIDS prevention, testing and care’ (Schenker 2006: 3), which includes the commitment to biomedical ‘explanatory models’ (Kleinman 1978) and ideally a process of conversion into responsabilised, active patient-citizens ready to stick to their side of their ‘treatment contract’^{xiii} – is the single most important factor in ensuring correct antiretroviral treatment adherence. Patients must undergo compulsory pre-treatment education sessions and be able to demonstrate sufficient treatment literacy to become eligible for the initiation of treatment. Failure to accept or adhere to antiretroviral treatment is frequently explained by patients’ ignorance and irrationality. However, lack of knowledge is not the main reason for low treatment uptake or adherence. As Niehaus^{xiv} suggests, far from being ignorant about HIV/AIDS, people show a super-abundance of information, provided by multiple diverse discourses, including conventional medical, religious, and lay discourses and rumours. This suggests that other factors are impacting on the efficacy of antiretroviral treatment programmes. In Zanzibar, these barriers include persistent HIV-related stigma, alternative diagnoses and healing approaches in a context of medical pluralism, widespread poverty and marginalisation, issues of gender, and concerns over individual agency and loss of control.

The complexity of HIV/AIDS epidemics requires us to look beyond statistical measures in evaluations of treatment programmes and provide a contextualisation of the ways in which ARVs are experienced.^{xv} An understanding of the social-cultural, religious, economic, historical and political context in which treatment programmes are rolled out is crucial to conceptualise people’s actions, highlights how structural factors constrain their ability to make choices, and unveils the rationality beyond apparently irrational decisions. Methodologically, such an approach implicates the need for long-term, in-depth ethnographic studies that analyse not only the ‘facts’ (of treatment uptake and adherence, CD4 counts and recovery rates), but also their underlying meanings.

While the new drugs have provided immense relief and transformed the situation of HIV-positive people from one of death and despair into one of hope and the prospect for a future,

they have also produced new uncertainties about how best to respond to HIV/AIDS, both for the infected individual and for society at large. Drawing on three case studies I show how HIV-positive people struggle to make decisions in an environment characterised by deep uncertainties about the nature and causes of HIV/AIDS in particular, and about the continuity of Zanzibari society in general. Emphasising the processual nature of disease and the importance of a contextual approach, this paper shows how interpersonal connections, individual experiences and emotions, and moral considerations at time take precedence over concerns about physical survival and points to the profound importance of social relationships and a view of life whose value is as much social as it is biological.

The data presented in this paper derive from 15 months of ethnographic fieldwork in Zanzibar in 2004-2005 and several follow-up visits in 2007, 2008, 2010, and 2011. Living with a local family and working closely with members of the Zanzibar Association for People Living with HIV/AIDS (ZAPHA+), Zanzibar's only support group for HIV-positive people, I participated in the group's daily activities, visited members' homes, and accompanied them to group events and on their visits to hospitals, relatives, and friends. Material was collected through qualitative methodology, using participant observation – a method resting on the in-depth study of social contexts and critical events particularly appropriate to a setting where shame and danger dominate people's lives.

An 'Immoral' Infection: HIV/AIDS in Zanzibar

The Tanzanian AIDS epidemic is strongly regional, with grossly differing prevalence rates in different geographical areas.^{xvi} Zanzibar is considered a low prevalence region in sub-Saharan Africa; while Tanzania's overall adult prevalence rate reached an estimated 6.2% in 2007,^{xvii} Zanzibar's estimated HIV prevalence was 0.6% in 2003, with women showing infection rates that are four to six times higher than their male counterparts.^{xviii}

Public discussion of HIV/AIDS in Zanzibar takes a strongly moralistic stance, playing on tropes of moral decay, outside influence and an overall increase in immorality.^{xix} Zanzibaris explain the comparatively low HIV-rates in the islands with their Muslim lifestyle, which many hold to protect its adherents from infection. Indeed, a large governmental AIDS commission sign at one of the major crossroads in Zanzibar Town reads: 'Our Zanzibari morals are an important protection against AIDS'. The fact that rates have been rising is regarded as an indicator for the breakdown of Zanzibari culture and proof of moral decline; it is frequently mentioned as a sign that 'the end is nigh'. It is difficult to calculate the influence of Islam on the unfolding of Zanzibar's HIV epidemic. While access to casual sex with multiple partners appears to be more restricted than for example in nearby Dar es Salaam, which has a much higher prevalence rate of 8.8%,^{xx} polygyny is common and non-marital sexual relationships are managed with a high degree of secrecy, which often precludes condom use. Condoms in general are not widely available, especially in rural areas, and difficult to access for unmarried people. Geographical isolation during the first years of the epidemic due to travel restrictions until the early 1990s, as well as the fact that the islands have not yet experienced a high-intensity generalised epidemic and have been offering good coverage of antiretroviral treatment since 2005, may be important factors that contribute to the relatively low prevalence rates.

Nevertheless, the perceived threat of AIDS in the population is high, and there is a great sense of uncertainty about the nature and the magnitude of the epidemic. This uncertainty has been heightened through HIV awareness campaigns that emphasise that one 'cannot tell who is HIV-positive by the looks of a person' (*huwezi kumjua mwenye UKIMWI kwa macho*) especially in

times of antiretroviral treatment. The epidemic has acquired a distinctive position that transcends the sphere of illness and medicine, and for the people of Zanzibar – as in other parts of Tanzania, Africa, and indeed the world – it has a meaning far beyond the individual suffering it causes.

While awareness of the major HIV transmission routes is high, the source of AIDS is located in the divine sphere: the prominent perception among religious leaders and the general population is that AIDS is a divine retribution (*adhabu ya Mungu*) for increasing immorality, embedding the pandemic in a local Muslim discourse on the erosion of Zanzibar's culture. In fact, the framing of AIDS as incurable led many to question whether it was a disease at all, since the Qur'an states that there is a cure for every disease. Therefore, many argued, AIDS had to be a direct punishment from God. The close association made between HIV/AIDS and what is classified as 'immoral behaviour' in Zanzibar, with a particular emphasis on illegitimate sexuality, has resulted in severe stigmatisation of HIV-positive people.^{xxi}

It must be pointed out that discourses which connect sexually transmitted diseases to illicit sexual behaviours are not solely informed by Muslim perceptions of sexual impurity and moral loss, but also reflect biomedical notions of disease in sub-Saharan Africa. In colonial Zanzibar, the hospital context, as a racially divided social arena, created opposing human categories along the lines of racial distinctions. As Vaughan argues, colonial medical discourse "operated by locating differences in the body, thereby not only pathologising them but also naturalising them".^{xxii} Consequently, in the creation of the colonial subject in Africa, notions of intelligence, character, and sexuality, and the mental and physical by-products of the human body, like diseases and insanity, followed notions of race.^{xxiii} In missionary discourse these diseases of race, associated especially with sexuality, were transformed into "diseases of immorality".^{xxiv} Indeed, HIV and other sexually transmitted diseases (STD) were labelled *wagonjwa wa uasherati*, 'diseases of sexual promiscuity' in educational posters produced by the Ministry of Health. Henceforth, public education against promiscuity and an emphasis on 'zero-grazing' (i.e. faithfulness to one, or a small, geographically close set of sexual partners), has been an important element in HIV prevention campaigns.^{xxv}

Uncertainty about HIV/AIDS in Zanzibar is counteracted by placing the disease in locally meaningful discourses about moral norms and values in a changing world, thereby restoring some sense of security and guidance for action. Knowledge of the biological processes involved in HIV transmission does not preclude this conceptualisation of AIDS in moral terms. Rakelmann e.g. points out that in Botswana the concept of the virus is entirely compatible with the idea of divine punishment: the virus explains *how* an individual is infected, and the sinful way of life explains *why*.^{xxvi} Zanzibaris argue, "If God wants to punish somebody, a condom won't stop Him – He'll just let the condom break", thus subordinating knowledge about biomedical concepts of infectious agents travelling from one body to the other to the notion of divine punishment for immoral behaviour.

Such discussions have sparked a strongly conservative response to AIDS in Zanzibar: the return to a life of Muslim values is promoted, and public discourse on sex and condoms is discouraged as fuelling promiscuous behaviour. In this context, many HIV-negative people initially were opposed to the costly treatment for people who, in their eyes, were largely responsible for their fate, fearing that the provision of treatment could lead to an even further relaxation of sexual mores.

'Medicines of Hope': Living with Antiretroviral Treatment

Within ZAPHA+, the island's only group for HIV-positive people, the promises the new treatment held were eagerly awaited and its success was celebrated: people who had been dying recovered miraculously, voluntary testing numbers shot up, and the trends quickly started to shift from final stage clinical diagnoses of AIDS towards early stage diagnoses of HIV as increasing numbers of people came to test. The introduction of routine testing has reinforced this trend. Yet, while these observations point to the success of the antiretroviral treatment programme at the population level, individual patients' trajectories suggest that antiretroviral treatment is often regarded as problematic, and neither treatment uptake nor adherence was guaranteed.

In Zanzibar at the time of treatment rollout, awareness of ART was low, and even within ZAPHA+ few members had heard of the drugs. Only the chairwoman Consolata, had been on a regular ART regime financed by her former employer, an international aid agency director, and one other member had used the drugs for some months before having to stop treatment due to the high cost. Only a handful of members had witnessed the drugs' remarkable potential, seeing Consolata's body recover quickly through the treatment. It is perhaps not surprising, therefore, that lobbying for access to treatment had not been a priority within ZAPHA+; the incentive for this came from external volunteers, including myself. Members spoke of their desire to live longer so they could make sure their children would grow up safely, and to regain strength so that they could work again and would not have to be a burden to their families any longer. "*Maisha yangu, kwa kweli, yameshaisha*, to be honest, my life is already finished," a mother of five told me, "if I could only live until my children have finished school, I would be grateful." To achieve this, ZAPHA+ members used various strategies: they tried to eat what they had learned to be a healthy diet, they boosted their immune systems with an array of vitality-enhancing substances and techniques, ranging from vitamin supplements bought at the pharmacy to prayers, they used hospital and traditional medicines to treat opportunistic infections, as well as protective medicines provided by traditional healers, and they constantly strove for creating and maintaining an inner peace which is considered vital for ensuring a healthy body. Antiretroviral treatment, at first, seemed just one more addition to this array of strategies.

Consequently, ZAPHA+ members asked for comprehensive information about the ways the drugs would work in their bodies. They wanted to know of the advantages and disadvantages of starting the treatment and an expert assessment of their individual health statuses by a doctor, so that each person could make an informed decision about whether to initiate the treatment, or rather to rely on established and trusted ways of handling the infection, including balanced nutrition and care for one's health (*kutumia chakula bora na kulinda afya*), and the use of various traditional medicines. This call for informed decision-making about their course of treatment is not taken for granted in the biomedical setting in Zanzibar: the hospital environment is characterised by a strong hierarchy that prescribes that patients should follow the doctor's advice without questioning, and health personnel often strengthens their authority by avoiding detailed explanation of diagnoses or treatment plans.

There has been much discussion of patients' non-compliance to treatment regimes in less-developed countries, with the biomedical community frequently blaming the patients for their alleged ignorance and obstinacy.^{xxvii} Responsibility has become obligatory for the 'active biological citizen', Rose and Novas^{xxviii} have pointed out: once informed about current illness, susceptibilities, and predispositions he is obliged to take appropriate steps in order to minimise illness and conduct life responsibly in relation to others. The enactment of such responsible behaviours has become routine and expected, and built into public health measures, and lies at

the heart of the biomedical profession's expectations – and their subsequent disappointment with 'non-compliant' patients.

But in developed countries, reports point mainly to patient- and treatment-related factors explaining low adherence, including substance abuse, the complexity of dosing and the 'pill burden' as well as side effects. In sub-Saharan Africa, on the other hand, financial constraints have been identified as a major obstacle to treatment adherence, including transport costs, hospital user fees, lack of food, but also long waiting times in the hospitals, fear of stigmatisation, side effects, and lack of counselling.^{xxix} Additionally, many of my informants complained that doctors and nurses are often unsympathetic, unfriendly, and prejudiced towards HIV-positive people. Finally, there is a general lack of explanation by health workers about what impact specific medicines have on the body and how different pills and injections work. As a result, people (and this includes HIV-negative people) often do not know the differences between medications they are prescribed, their names, the ways the active ingredients have an effect on their bodies, and why they were prescribed this drug and not another. Patients sometimes divide or exchange medications, following colour schemes and pill sizes that are associated with effectiveness for specific complaints, rather than considering the drugs' biomedically active ingredients. Reporting from a small private research centre in Burkina Faso, on the other hand, Nguyen shows that essential to the success of its AIDS treatment programme has been the physician's ability to foster an institutional culture that enables – in Foucault's terms – disciplined patients. This was achieved by dissolving the hierarchy between patients and physicians through familiarity and friendly treatment and by instilling a culture of explanation.^{xxx} Nguyen's account is not the only one pointing in this direction: Paul Farmer, for example, has long argued against the perceived ability of individuals in poor countries to follow the rational choice model promoted by biomedical physicians, and draws on various cases that show that when barriers against access to effective care were removed the differences between the survival rates among the poor and the wealthy disappeared.^{xxxi}

The following case studies shed light on the complexities involved in apparently irrational decisions around antiretroviral treatment, emphasising how – within the limits of structural constraints – people actively make choices and carefully weigh the potential consequences. They demonstrate the deep social embeddedness of decisions about ART, which are bound up in social, economic, political, and moral contexts.

The Risky Commitment to Life-Long Treatment: Fatma and Amila

Fatma and her daughter Amila's lives were quite characteristic of the experience of living with HIV/AIDS in Zanzibar. Fatma was 27 years old when I met her the first time at ZAPHA+. She was born in Pemba and married off at the age of 14. She did not really want to get married, but she did not want to appear ungrateful and oppose her parents. After she had one son, her husband divorced and left her with the child. She was forced to go back to her parents' house, where she lived for a few years. But the pressure on her to get married again was mounting, so finally she agreed to become the third wife of an older 'Arab' man (as she described him), which is not uncommon for a divorced woman. This man's first two wives had failed to produce any offspring. Fatma noticed early on in the marriage that her husband was constantly suffering from headaches and other ailments and that he was taking Panadol almost every day. Nevertheless, she got pregnant and gave birth to a daughter, Amila. Seven months later, her husband suddenly died. Only then she found out that he had died of AIDS and known of his HIV-positive status when he married her. But he was afraid to die without having any children. So when he tested HIV-positive, he married a second wife and four months later a third – Fatma.

He left three wives and his only daughter HIV-positive, the little girl being close to death in the summer of 2005. After her husband had died, Fatma went back to her father's family, a household of 22 people, all relying on one income. She did not think that she had done anything wrong, but she still felt ashamed about her HIV infection and was afraid of her family's reaction if they found out; surely they would send her away and call her a prostitute, so she had not yet managed to tell her family about her disease.

Evidently, this situation made it difficult to keep up with strict treatment regimens and even to obtain the nutritious food that is vitally important for people living with an immunodeficiency disorder. Although Fatma had not told anybody yet, she thought that some of her family members suspected that she suffered from AIDS, as they refused to eat from the same plate as she and her daughter did. Asked about her dreams, about how she envisages her future, she replied, *sasa hivi nipo tu*, 'I am just here now'. 'I can't do business because I get too tired, and I have to take care of the child. And if the people find out that you're HIV-positive they won't buy anything from you anyway. Everybody is afraid of you, they don't even give you any sympathy. When I was a child I dreamt of studying, I wanted to be a teacher or a doctor, but now I'm too old to study. The sun has already set, why should I study anymore?'

While her own CD4 was still fine then, her daughter's health status was very poor and the doctor advised her daughter start the treatment. This gave Fatma hope to see her child grow and get better. On the other hand she was also very worried: would the drugs be available in the future? She did not even have the money to buy basic food, let alone expensive Western drugs. And would her daughter have to take pills for the rest of her life? Would it not be better to use vitamin supplements, or take her to the traditional healer to 'build up' her body first? After much deliberation, Fatma decided to start the treatment.

Amila was one of the first children in Zanzibar to receive antiretrovirals, and when she started the treatment she was already very sick; I thought she was going to die. Although she was very good in swallowing all the medications, she often could not keep them inside: she was feverish, could not eat, and constantly vomited. Her mother – being almost illiterate – at first had problems in administering the right dosage (paediatric ARVs come in fluid form and must be mixed and dosed with the help of a syringe), and in filling in the monitoring forms. Moreover, Fatma always had to be there and administer the drugs herself, because nobody else in the family knew about her and her daughter's health status, so when there was no food in the house, or Fatma was away, Amila missed her dose. Despite these problems, Amila slowly started to get better, and seeing her again in July 2007, I could hardly believe that this was the same child. The sad-looking tiny girl, who never smiled nor spoke, had grown into a healthy-looking five year-old who happily played with the other children.

However, by then Fatma's own health status had deteriorated and the doctor advised her to start treatment, too. Yet, although she had seen her daughter regain strength and grow over the past two years, Fatma did not think she would take the drugs herself. "I've got them at home", she said, "but I thought I'd better wait until I have more food to eat. You know how it is at home, I only eat one meal a day, and often not before 2 or 3 pm. These medicines are strong – how can I swallow them without having eaten?" While Fatma could justify spending an extra amount of money on food for Amila, because she was a child and obviously ill, she could not put herself before other members of her family and expect them to provide her with more food than they had, especially her father, the head of household and sole breadwinner. This would have stretched her social support network too much. She was not even visibly very ill – not more than the others, at least, who also suffer from bouts of malaria and other infections. It took her

another five months until she finally decided to use the life-prolonging treatment that her body so urgently needed.

Fatma's story elucidates several of the uncertainties brought up by the treatment of AIDS in Zanzibar. Firstly, there is a strong fear of dependency in the context of distrust of the government and the international donors: Fatma had learned from experience that promises made by the government were not necessarily reliable,^{xxxii} and the behaviour of international donors was completely out of her control: after the 1995 elections riots, for example, most international donors had pulled out of projects in the islands, leading to service delivery projects being starved of funds. Moreover, corruption was thriving in Zanzibar, and hospital staff were suspected of starting to charge for the drugs once the funding agency handed the project over to the local authorities. Embarking on a life-long treatment programme therefore meant giving up agency to a large extent and becoming dependent upon authorities that are far beyond 'normal' people's control and may have hidden agendas. Whyte, van der Geest, and Hardon^{xxxiii} point to the ambiguity of control inherent in the use of medicines, highlighting the constant field of tension between self-control over the infection versus society's control over the sufferer, which patients have to negotiate. ARVs offer the opportunity to regain some control over one's body and life, providing the patient with the strength and health to resume productive and reproductive activity. At the same time, ART also meant giving up a good deal of control over one's life and handing it over to an unreliable government and to donors who are fickle in their attachment.

Patients were very aware of these uncertainties: the first question always asked in information sessions on antiretroviral medication was: 'will the drugs be available and still free of charge in two, five, ten years' time? What happens if the donors pull out?' In their research on the channels ARVs flowed through in Uganda before the introduction of free treatment in June 2004, Whyte et al.^{xxxiv} point to the necessarily tough prioritising of family funds and the resulting intra-familial moral dilemmas, the terrible decisions of triage, and the growing awareness of inequity that result from the availability of ARVs for payment of a fee in a country where most people cannot afford them. My research participants' concerns were well-founded, as none of them would be able to pay for antiretrovirals without seriously stretching their social support network and using resources that are greatly needed for other investments – in fact, most of them could not pay for the drugs at all. At the same time, the rollout of free antiretrovirals in combination with a crumbling public welfare system and an increasing withdrawal of the state from the provision of social services as part of neoliberal reform packages painfully draws to attention the combination of biological inclusion and social exclusion which features in Biehl's^{xxxv} critique of contemporary biopolitics of AIDS in Brazil.

Another concern many have with top-down biomedical interventions are the hidden agendas suspected to form their background. Although Fatma had not mentioned this explicitly, other programmes have triggered such discourses. The colonial government's anthrax immunisation project, for example, was widely regarded as an attempt to kill the people's cattle, and led to severe riots in the country that finally resulted in the strengthening of party politics.^{xxxvi} In 2008, a vaccination campaign sparked violent riots in several hospitals in the country. Family planning messages, likewise, were taken to be motivated by the West trying to limit the reproduction of the African people and to impose their lifestyle upon Africans, with condom promotion in particular being viewed as fuelling the immorality that had already started to spoil Zanzibar society. To what extent these kinds of discourses play a role in the treatment of AIDS still needs to be seen in the future.

Fatma also had concerns about the nature of the medication itself and its effects on the body. Her worries about the side effects need to be considered in the context of constant food insecurity and her experience with Amila and some other HIV-positive friends. Western medicines are perceived as very potent, and therefore potentially dangerous. In the hierarchy of medicines in the area, Western pills rank second to injections only. At the same time, there is not much knowledge about the ways specific drugs work in the body of the patient – pills are often discriminated by their colour and size, rather than the specific illness they are supposed to treat. Rumours about biomedical technologies such as pills or condoms) causing cancer, impotence, barrenness, or miscarriages are omnipresent and partly supported by medical evidence.

Finally, vitality enhancing medicines, including vitamin supplements sold over the counter at the pharmacy, certain nutritious foods, and a range of traditional medicines that aim specifically at strengthening the body, are popular and often preferred to hospital medicine, especially in cases of paediatric AIDS. Even in the case of ‘normal’ illnesses, parents often ponder for days about subjecting their children’s small, vulnerable bodies to the potential toxicity of medicines. Another girl of Amila’s age, for example, had developed painful fungal infections in her mouth. She could not eat anymore, lost weight rapidly, and had constant fevers. The doctors advised to start her on AVR, but her caretaker declined, being too concerned about the dangers of the medication. She decided to boost the girl’s general health status by buying expensive vitamin supplements and to wait until the child could eat again. Despite her caretaker’s efforts the girl died a few months later.

Together, these concerns form the context in which Fatma made her decision: despite seeing her daughter improve significantly over the past two years with the help of ARVs, she chose not to start the medication, as the risks of committing to the lifelong treatment for her seemed to outweigh the benefits. However, such decisions are not final, and individuals change their minds, for example when they start feeling ill, or when their life circumstances change. With deteriorating health and constant counselling by ZAPHA+ peers, Fatma finally started treatment in July 2007, but her adherence was patchy, reflecting her strained social relations and economic position. Such intermittent treatment trajectories highlight the processual nature of illness, with individual actors often taking different positions in the course of the illness, both in trying to explain the cause of the suffering, and in the preferred routes of treatment.

Fatma had been confronted with the grim reality of the disease through her daughter’s illness – AIDS was omnipresent for her. Her concerns about treatment revolved around issues of availability of food and drugs, around the strong side effects, and the difficulties of adhering to the treatment regime when she could not fall back on the support of her family. In the end, reflecting on the stigmatisation she had experienced, she said: “Why would I want to live longer, if nobody wants me around anymore anyway?” Her only reason to live, she thought at the moment, was to make sure her daughter was taken care of, and this in the end swayed her decision towards starting the treatment in 2007. However, she stopped treatment again when she got pregnant three years later for fear of harming the unborn child, and died shortly after the baby’s birth.

Measuring Life-Time Left: Tausi

With Tausi, a 30 year old woman, the situation was different. Tausi was working and her regular income made her economically independent. Therefore, food, and even moderate payment for medication, was not such a problem for her. She largely trusted in biomedicine, and once she had started the treatment, she did not have problems with adhering to the regime. In her case,

the decision to start using ARVs was complicated by the fact that the accessibility of the treatment forced her to face her health status again.

She explained: 'When I had my initial HIV test and it was positive, I thought my life had stopped. Everybody says: AIDS kills – and I had it'. Then she joined ZAPHA+, where she learned about the difference of 'living with HIV' and 'being sick with AIDS', which is emphasised in HIV/AIDS education sessions. Tausi embraced the international discourse of living with hope, and slowly started to accept her infection. In her quest for normality she did everything she could to redefine her condition in a positive way and to live a 'normal' life. This is often perceived as denial by outside onlookers; but Tausi had never denied her diagnosis. She was aware of it every day, but she refused to accept that she was going to die any time soon.

When the drugs became available, however, her carefully built construct was tested and fundamentally shaken. The CD4 count that every HIV-positive person was advised to take to establish disease progression painfully called to her mind that she was not, in fact, leading a normal life, that the infection was still there and might have progressed. But she felt healthy and strong, so she was not too worried. There were others, who were sick all the time and very skinny. They would have to start the medication. On the day before her CD4 test she said: 'I feel great, I have gained weight, and even my mother finally starts to believe that I will live and grow old with the infection.' And yet, it turned out that her CD4 was well below 200 and she had to start ART immediately. She was devastated. This test was such a shock to her that she later told me: 'Receiving this diagnosis was worse than getting the initial HIV-positive result. I thought, now I really am going to die'.

Tausi's case is exemplary of the thoughts and fears of many of my informants when treatment finally became available. While being excited about the comforting assurance that now there was something you could do once you fell ill, only few people were eager to start treatment. Rather, the accessibility of medication served as a reassurance, an opportunity for those times far away when the virus would take over the body. For as long as possible, however, a life without the strong drugs was desired. At the same time, the repeated confrontation with the disease was emotionally distressing, especially for those who felt healthy. After all the efforts to build up their new life after the HIV test, carefully constructing a fragile sense of normality in which they are HIV-positive, but not sick with AIDS, now their health status was revised again. The initial HIV test had shattered my informants' lives and drew a boundary, segregating them from the world of the living, the 'normal', HIV-negative members of society. Through the CD4 count again boundaries are drawn – this time within the community of PLHA, once more segregating members who had tried to build up new networks of solidarity. Becoming eligible for treatment initiated the person into the group of 'proper' AIDS patients. It meant that the end was near, that the person's life-time was running out.

But it was not merely the confrontation with the infection that was distressing to my informants. The nature of the test itself, its biomedical claim to authority and absolute truth, was considered problematic. While diagnoses by traditional healers are usually produced in collaboration with the patient and other members of the social network, and are always open for reinterpretation and adjustment, the CD4 count pushes the individual into a passive position. This process of measuring a person's health status, and thereby their remaining life-time, transforms persons into patients and takes away their agency, subjecting them to 'objective' tests that often do not reflect how healthy a person feels. Again, an anonymous lab test would decide about their lives – after spending so much energy on getting their lives under control after the initial test. The diagnosis was thus sometimes questioned, and trust in the authority of the health personnel and quality of counselling once more played a crucial role in deciding on the best course of action.

Competing Authorities: Aziza

The story of Aziza, a young woman who died in June 2005, brings up a completely different set of issues that influence a person's decision about whether to use antiretroviral treatment. Aziza had been diagnosed with final stage AIDS and was in hospital. She had had an HIV test before, which was positive, but she did not believe in the diagnosis. Instead, she trusted in the expertise of a traditional healer who had diagnosed her with a witchcraft affliction (*kurogwa*) and administered anti-witchcraft medicine, purgatory agents that made her vomit and caused diarrhoea in order to expel the witchcraft agent from her body. By the time she was admitted to the hospital she was severely dehydrated and weak. But even in the hospital, and despite repeated counselling, she carried on with the anti-witchcraft medicine. She finally died all by herself, because her family never visited her in the hospital – they only came to pick up her corpse when they were informed that she was dead.

Aziza's story reminds us of the fact that there are experts other than biomedical doctors, who are consulted and trusted by the majority of the population. And there are theories of disease causation that differ from the biomedical model of infectious agents invading the body. Lab-based diagnostics and antiretroviral treatment have to compete with these models, and if we consider the local context, the witchcraft idiom becomes quite appealing. In an environment where AIDS equals adultery and immorality, and the victims face stigmatisation even by those closest to them, the witchcraft explanation requires an analysis of the whole network of social relations and thus deflects blame away from the individual, placing responsibility on the larger group.

Moreover, an explanation using the witchcraft idiom (or the notion of divine retribution) opens up possibilities and routes for action: healers are consulted and different treatments are tried out – each offering the prospect of a cure. And while my informants praised the introduction of antiretroviral treatment, a cure (*kupona kabisa*) is what they were really hoping for. Consequently, the majority had already tried out one or several traditional treatments that promised to eradicate the virus completely, and frequently news about some new medicine against AIDS arrived. People went home to their villages to seek out their own healers, and bought medicines from all over the country, from places as far away as Kagera (where the Tanzanian epidemic had started and thus people were assumed to have a lot of experience with treating it), Dubai, or Saudi Arabia. In 2011, six years after treatment rollout, thousands flocked to rural Loliondo to drink a 'miracle brew' conceived of in a local pastor's dream, and many died en route. Herbal concoctions (*dawa za miti shamba*), the composition of which would come to the healer in a dream or through the help of spirits, and fumigations (*fukizo*, 'incense burning'), often in combination with Qur'anic supplication (*dua*), were administered and supported through prayer and abstinence, following the way of the scriptures.

Traditional doctors seemed to be making a good business out of this,^{xxxvii} to the extent that in 2004 all advertisements that claimed to offer a cure for AIDS were made illegal. This is however not to say that their attempts were all purely focussed on making a profit. Some healers seemed to be genuinely concerned about finding a cure and I came across several cases where treatment was offered for free. Stories about successful cases came up again and again and kept kindling hopes, despite the fact that most of my informants were repeatedly disappointed. After all, who knew what the real cause of the treatment failure was? According to Parkin, religious and spiritual beliefs survive empirical challenges because faith may always be invoked to provide answers that biomedicine or traditional herbalism do not: along the lines of the principle of

secondary elaboration as enunciated by Evans-Pritchard in his study of Azande divination and cure, the apparent failure of divine or spiritual treatment can always be ascribed to the improper performance of the ritual and procedure; Muslim prayers said before a biomedical treatment, for example, must be said sincerely and properly, if they are to work. This is consistent with the view in Zanzibar today that the Qur'an is the ultimate medicine and source of scientific knowledge,^{xxxviii} and is supported by the belief that God can cure any disease.

ARVs, the doctors clearly emphasise, cannot offer such a cure. Yet, the definition of illness as having an infectious agent hide somewhere in the body, waiting for its chance to strike, for many was hard to understand: "If you are not ill (*kama huumwi*), if you don't feel pain, or lie in bed, but go out to do your work as usual, then how can you be sick?" a young man explained, "what does being sick mean, then? I might have a virus in my body, so what? I'm not sick." In Zanzibar, as elsewhere in the region, illness is associated with incapacitation. Health, here, is the absence of illness, of pain, weakness, and the inability to work. If ARVs can restore the body to a state in which it functions as good as normal, then for many this meant that the person is healthy again. Indeed, when I revisited the island over the following years, some of my informants had stopped taking the drugs, considering themselves cured when they started to feel better.

However, these were a minority; most ARV receivers had remained on treatment, especially those who had been with ZAPHA+ since before treatment was available. They had experienced the treacherous nature of AIDS, with periods of succumbing to illness, temporarily getting better after the treatment of opportunistic infections, and worse again only a short time after. They had found ways to explain the work of the virus and of the drugs in people's bodies, and continuously argued against stopping the treatment. "The ARVs put the virus to sleep (*virusi vimelala*)," they explained, "it hides and rests somewhere in your body". "But when you stop the treatment the virus comes back stronger than ever and kills you very quickly." The view of the virus as a 'bug' (*dudu*) which can be put to sleep was combined with local views on appropriate behaviour and the effects of sex on the body in explanations that emphasise the need to refrain from excessive sexual activity: "When you have sex the blood becomes hot and flows faster; this wakes up the virus and it begins to circulate through your body", a ZAPHA+ member explained.

Never promising more than a longer life span, in official medical education sessions ART was presented as *dawa za kurefisha maisha*, 'medicines to prolong life'. But despite all the new kinds of uncertainties the new treatment has provoked, in ZAPHA+ discourse they soon became *dawa za matumaini*, 'medicines of hope'. Antiretrovirals build up the body, it was argued, so that it endures until finally a real cure will be found. In this sense, ARVs may be classed as yet another, albeit powerful, vitality enhancing medicine. This is supported by the heavy emphasis laid on techniques to guard one's health (*kulinda afya*) through quality nutrition, appropriate amounts of rest and exercise, and a morally sound lifestyle. Much trust is invested in the prospect that a cure will be found one day, either through biomedicine or 'traditional' healers. Thus, the diagnosis of HIV in the end is not as final as it may have seemed – some scope for hope, and for action, always remains.

Hoping for a Good Death

At the same time, most of my informants had accepted the thought that they would most likely die from AIDS one day. But how would this death come about, under the new antiretroviral treatment? The antiretrovirals prolong patients' lives – but would they in the end still die as terribly as their fellow sufferers before? This was one of the most pressing questions always

posed in conversations about ART. Dying from AIDS was clearly a 'bad death': One day, Rahma, an HIV-positive woman in her fifties and long-term member of ZAPHA+, brought photographs of her late sister for me to look at. The first picture showed a big, laughing young woman in a bright, colourful dress. "This is before her infection," Rahma explained. The next one showed the same woman, weighing a little less maybe, but smiling, with beautifully smooth and clear skin. "This is in April, after she had just received the diagnosis." The last picture features Rahma, sitting on a bed next to her sister on the day before she died. Amina and Khamis, two other members who are watching together with me, are as shocked as I am at the sight of this wasted body – we cannot recognise the woman from before; she is mere skin and bones, covered in rash, looking ancient. "This is a bad disease," Amina said quietly, and I could read her thoughts: will I die like this? The prospect of escaping from this fate, of growing old and dying in dignity, is what the 'medicines of hope' symbolised for my informants. Whether it will be fulfilled is hard to say; from a biological point of view, if the treatment fails the virus is no longer suppressed and the disease progresses to AIDS.

Many of those ZAPHA+ members who had witnessed the introduction of ART are still alive today because of the drugs, and actively promote treatment uptake and adherence as peer counsellors and home-based carers. Newly diagnosed patients therefore encounter a better organised network of peer support and information within ZAPHA+ and the HIV clinic. Nevertheless, there are signs that drop-out rates are increasing, for a number of reasons. Fear of stigmatisation still makes it difficult to take the drugs when in the company of others, e.g. at work or within the family, and social and economic support and home-based care programmes have been reduced significantly due to funding cuts. Moreover, widespread treatment provision and routine testing policies have brought AIDS into public discourse and result in many now being tested in early stages of infection and have not yet experienced serious opportunistic infections, thus lacking the powerful experience of the drugs' work in restoring their health. Without the experience of severe symptoms it has become increasingly difficult to convince people to stick to lifelong treatment regimes. These are issues which will need consideration with maturing treatment programmes across the region.

In Zanzibar, specifically, religious and moral concerns pose additional hurdles. Fasting during Ramadhan, for example, is an important religious requirement and a highly respected social activity, but interferes with the strictly time-bound treatment regimes. While the sick are exempted from fasting in Islamic doctrine, HIV-positive people on treatment face competing messages about their status: clinic staff emphasise the 'chronically sick' identity of PLHA, whose lives depend on following the strict treatment regimes. At the same time, according to the language of international HIV/AIDS programmes, successful treatment restores patients' health and affords them a 'normal life, just like any other person'. Many are eager to take part in the collective experience of Ramadhan, others are worried about having to explain why they do not fast. An elderly widowed woman in the rural east, whose health was poor, explained: 'I'm not sick, I'm just disabled (*siumwi, ni mlemavu tu*). Even if you bring that Islamic scholar again to lecture me, I won't stop fasting!' As a result, clinic staff report falling CD4 counts and rising opportunistic infections during and after Ramadhan in the islands.

Yet, most people in Zanzibar were treatment-naïve and by 2011, ART resistance was still low. Death was not a pressing worry anymore. Concern was focused once more on the topic which preoccupied most people's lives: impoverishment and the difficulty of making a living in what was perceived as an increasingly tough life, *maisha magumu*.

Conclusion

The vignettes in this paper show how patients make sense of and respond to the uncertainties of illness and treatment through social relations. They demonstrate that the social, economic, moral, and political contexts in which mass treatment programmes are rolled out are profoundly important for treatment uptake and adherence. In their decision-making, people fall back on previous experiences with the healthcare system and with promises made by the government and international donors, they consider their network of social relations, moral concerns and individual emotional factors. Treatment literacy played a relatively minor role in predicting the success or failure of antiretroviral treatment in Zanzibar; rather, concerns revolved around questions of control and agency, limiting structural factors, and alternative aetiologies in the context of medical pluralism.

These findings confirm Allen and Parker's^{xxxix} claim that a pharmaceutical approach is not sufficient to tackle complex epidemics like HIV/AIDS. Health interventions cannot be orientated to 'life itself'; they must be attuned to the contexts in which life takes place: the family, the community, the structural inequalities that make some treatment decisions and practices of self-care easier and others more difficult. ART programmes make possible a biologised, pharmaceutical life. But life-as-lived must be shared with others. Therefore, shifting funding streams to drug provision without a comprehensive prevention and clinical care approach, and expecting patients to make the 'right' choices in the face of structural constraints and competing messages, ignores the fact that patients are persons, social beings who relate with and depend on others to survive and live a good life.

Analysing people's actions and behaviours in the context of their lives-as-lived throws light onto apparently irrational decisions and emphasises the importance of an in-depth understanding of local moral worlds and social contexts. Life with a chronic illness is a messy, emotional and uneasy process that involves uncertainty, anxiety and self-doubt, a need for sharing with others in a similar situation, and for support and kindness from service providers. In the global North, AIDS today is largely addressed as a chronic illness, with support systems going far beyond the dispensing of drugs. In the global South, however, AIDS continues to be treated in emergency mode, as an acute infection which first and foremost requires pharmaceutical treatment, while social support programmes such as home-based care, peer support, and livelihood provision are increasingly cut in order to get more patients on the treatment registers. What these case studies clearly show is that the management of a life-long chronic condition cannot be tackled on a biological basis alone. Treatment has to be made meaningful and embedded in people's social lives in order to work and achieve patients' commitment to adherence.

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ⁱ For a detailed account of the global AIDS Treatment Access Movement, albeit presented largely from a US American point of view, see Smith and Siplon 2006.

ⁱⁱ UNAIDS 2012: 9

ⁱⁱⁱ UNAIDS Press Release, 19.7.2012

^{iv} WHO News Release, 12.7.2012

^v Biehl 2007

^{vi} Biehl 2007; Nguyen 2010

^{vii} Cf. Parker et al 2012; Allen and Parker 2011 and 2012

^{viii} Allen and Parker 2012

^{ix} Whyte 2012

^x Rose 2007

^{xi} Fassin 2009: 48

^{xii} Ibid

^{xiii} Beckmann forthcoming

^{xiv} Niehaus 2009: 18

^{xv} McNeill and Niehaus 2009: 119

^{xvi} Cf. Leshabari et al. 2005

^{xvii} UNAIDS 2008: 215

^{xviii} ZAC 2003: 1

^{xix} Beckmann 2009

^{xx} THMIS 2007

^{xxi} Beckmann 2009

^{xxii} Vaughan 1991: 13

^{xxiii} Nisula 1999: 244. Some observations on patterns of condom use in casual sexual encounters on the tourist beaches in Zanzibar suggest that these racial notions still live on today: several backpackers said they often used condoms with African lovers, less frequently with other white travellers.

^{xxiv} Vaughan 1991: 66-67. Note, for example, reports from the Zanzibar Medical Officer in which the prevalence of venereal diseases was attributed to the natives – particularly the women – being ignorant, immoral, and engaging in casual prostitution (Nisula 1999: 243).

^{xxv} Iliffe 1998: 223

^{xxvi} Rakelmann 2001: 45-6

^{xxvii} Cf. Farmer on tuberculosis and antiretroviral treatment (2001: 191-9, 208, 268-71).

^{xxviii} Rose and Novas 2005

^{xxix} WHO 2006: 1, 7

^{xxx} Nguyen 2005: 139

^{xxxi} Farmer 2001: 266-71

^{xxxii} One may only think of the allegedly free provision of education and health care, which in fact both had to be paid for.

^{xxxiii} Whyte, van der Geest, and Hardon 2002

^{xxxiv} Whyte et al. 2004

^{xxxv} Biehl 2007

^{xxxvi} Babu 1991

^{xxxvii} Payments usually ranged between TSH 150000 and TSH 500000 – expensive, but not unaffordable. Many of my informants had mobilised their social networks to raise it.

^{xxxviii} Parkin 2007

