

# **Responding to medical crises: AIDS treatment, responsabilisation and the logic of choice**

Nadine Beckmann

## **Abstract:**

The framing of HIV/AIDS as a crisis has facilitated the rollout of large-scale intervention programmes that represent an enormous effort at mainstreaming biomedical rationalities and neoliberal notions of responsabilisation and self-care. Based on a 'logic of choice' (Mol 2008) and 'responsibilised citizenship' (Robins 2005a), though veiled in a language of rights and partnership, the heavy focus on individual behaviour and a pharmaceutical 'solution' to AIDS shifts the burden of responsibility for the success of the heavily funded programmes onto the shoulders of the patients and conceals alternative forms of responsibility. Analysing how HIV-positive people in Tanzania navigate life with HIV and the complex treatment regimens, this paper looks beyond biomedical rationality, which places the preservation of individual biological life at the centre of its logic, and analyses people's constant struggle to negotiate the meaning of 'responsible behaviour' in the context of their lived realities. This repositions the notion of responsibility in the realm of the social and reveals the rationality behind apparently irrational practices.

*Keywords: Tanzania, responsabilisation, risk, uncertainty, choice, antiretrovirals*

## **Introduction:**

Crisis rhetoric has characterised discourses about HIV/AIDS from the outset. Its fatal course, the lack of a cure, and the terrible suffering it caused made it known as the 'killer disease' of the twentieth century. Initially associated with stigmatised 'high-risk groups' and framed as a moral crisis, the pandemic came to be regarded as an 'unprecedented crisis that requires an unprecedented response' and a 'threat to development itself'<sup>1</sup> when the full scale of HIV/AIDS in Africa became visible.

This successful framing of AIDS as a public health and development crisis has produced the largest funding mechanisms for a single disease the world has ever seen and an exceptional level of effort invested into the 'global fight against AIDS' in an emergency response which frequently circumvents older power structures. Reminiscent of the workings of what Naomi Klein termed the 'shock doctrine' (2007), this emergency response to AIDS made it possible to push through previously unimaginable agendas and release huge resources. In 2008 alone, at the peak of the AIDS funding era, an estimated US\$14 billion was spent on HIV/AIDS worldwide (Sidibé 2009), funding HIV prevention, care and treatment programmes. In many of the hardest hit countries, AIDS funding accounts for a major part of national health expenditure, the bulk of which is donor-funded.

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<sup>1</sup> Kofi Annan in his address at the XV International AIDS Conference in Bangkok, 2004.

The concerted global effort in the fight against AIDS has helped to create new socialities, including the expansion of PLHA<sup>2</sup> support groups, new forms of narrative practice and new global webs of connection between people heretofore totally separate. But the strong dependency on donors also makes HIV/AIDS programming a prime channel for the mainstreaming of biomedical knowledge and a means of regulating the most intimate spheres of people's lives. Often characterised by an 'all-or-nothing' rhetoric, large-scale intervention programmes aimed at raising knowledge and awareness were directed at the general public, urging people to change their behaviour if they were to live, or else choose death. Since the mid-2000s, mass treatment programmes keep those alive who are already infected, following a similar intervention logic. Nguyen analyses these interventions as a new form of 'therapeutic domination' (2009: 201) which results from framing the epidemic as a humanitarian emergency. Drawing attention to the vertical and donor-driven nature of the programmes, which runs counter to their rhetoric of 'partnership' and 'collaboration,' he argues that AIDS defines 'exception' in political terms as an issue that may partially suspend national sovereignty and lead to the emergence of new forms of de-territorialised governmentality (ibid: 211). The shift towards antiretroviral treatment, in particular, has expanded a 'therapeutic apparatus' to define and make available populations for treatment and to monitor, record and track patients (ibid: 202).

This paper directs attention to the promotion of scientific rationality and Western neoliberal notions of responsibility and self-care through such programmes, and highlights how these tend to overshadow alternative forms of responsibility. AIDS intervention programmes represent an enormous effort at mainstreaming biomedical knowledge and directing individuals' sexual behaviour and patterns of romantic involvement. They rely on a neoliberal model of healthcare which emphasises the entrepreneurial, free and autonomous individual who is capable of caring for themselves. The intimate technologies used, such as counselling people to be abstinent, faithful or use condoms, and become responsible patients actively involved in ensuring successful treatment outcomes, 'target the way in which we care for our bodies, constitute our families, talk to our lovers, raise our children, as well as our sexuality' (Nguyen 2009: 205). By analysing imperatives of living positively and responsibly with HIV in Tanzania, it is argued that the formation of what Annemarie Mol has called a 'logic of choice' (2008) and the promotion of responsabilised citizenship, though veiled in a language of rights and partnership, works to shift the burden of responsibility for the success of the heavily funded programmes onto the shoulders of the patients and promotes a concept of life whose value is predominantly biological.

The data drawn on derive from more than two years of ethnographic fieldwork in mainland Tanzania and Zanzibar since 2004. Working closely with HIV-positive people, HIV prevention and treatment interventions have been tracked from before ARVs were introduced in the country to the present. The author conducted participant observation

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<sup>2</sup> People Living with HIV/AIDS.

and semi-structured interviews in HIV clinics, support groups, and the homes of HIV-positive people, collected life histories and followed discussions about HIV/AIDS, morality and sexuality in the public arena and in the privacy of people's houses.

After a brief introduction to the concepts of responsabilisation and the logic of choice, some of the factors that hamper the emergence of responsabilised citizens in Tanzania are highlighted. Then the underlying meanings of the concepts of responsabilisation and choice and their disciplinary impact on HIV-positive people's lives are analysed. Contrasting the actual uncertainties of life with the scientifically-framed discourse of certainty, it is argued that HIV-positive people constantly negotiate the meaning of 'responsible behaviour,' taking their social environment as well as their biological status into account. It is proposed that the notion of uncertainty is better suited than the concepts of risk and responsabilisation to make sense of the complex processes of decision-making around HIV/AIDS in Tanzania. The paper concludes with considering an alternative logic, the logic of care, as more appropriate to address the complex situations of choice HIV-positive (and many HIV-negative) people in Tanzania face.

### **Responsibilisation and the logic of choice**

Largely inspired by the need to find ways to ensure adherence to life-long antiretroviral (ARV) treatment regimes for AIDS, a debate has recently been revived among academics, public health experts and activists around contractual forms of obligation between patients and health care providers. Some public health experts (cf. David Coetzee and Helen Schneider 2003) have acknowledged that authoritarian models of direct observation therapies, as used e.g. in tuberculosis treatment, are not a viable solution for the monitoring of life-long ARV treatment adherence. Instead of over-riding individuals' rights to bodily autonomy, free choice of testing, and ARV treatment with reference to the state's responsibility to protect the public from infection and drug resistance, they have called for a new 'contract' between health care providers and clients which emphasises the need for highly motivated, treatment-literate 'patient-clients' for antiretroviral treatment to work. In this contract, the 'responsibility for adherence is given to the client within a clear framework of empowerment and support' (Coetzee and Schneider 2003: 772).

Analysing South African AIDS activism, Steven Robins (2005a, 2005b) describes the process of responsabilisation of patients into active health consumers as one of empowerment, turning patients into rights-bearing responsabilised biological citizens. Merely providing education about rights and responsibilities, he points out, are insufficient to create responsabilised patients. Instead, Robins suggests that it is the experience of physical deterioration and social death, combined with the support and social belonging acquired through participation in AIDS activism through social movements like the Treatment Action Campaign and Médecins Sans Frontières, which

has produced the conditions for a commitment to 'responsible lifestyles' and 'active citizenship.'<sup>3</sup> (2005a: 3). The discursive power of interpretive frames of illness, expressed for example in powerful treatment testimonies, he argues, facilitates those transformations in HIV-positive people's subjectivities and identities deemed necessary for a successful response to HIV/AIDS, both in terms of treatment and prevention (Robins 2005b: 4).

At the same time, notions of responsabilisation and contractual forms of healthcare provision resonate with a recent body of literature on the expansion of medical technologies in advanced liberal societies, which argues that a biological definition of life has become central to our notions of self and to politics. Analysing forms of governance emerging in late 20<sup>th</sup> century Europe and North America, Miller and Rose (2008) show how in liberal societies – where individual privacy was paramount and the state had its limits – authorities increasingly started to interfere in people's intimate spheres of life at a time when the state began to withdraw and notions of choice and the entrepreneurial self began to gain ground. Building on Foucault's governmentality approach, social theorists such as Peter Miller, Nikolas Rose, Carlos Novas, and Ulrike Kistner show how new technologies of government have emphasised the responsibility of individuals to manage their own affairs against a background of an emerging concept of 'risk': a new style of thinking which brought the future into the present and made it measurable through statistical calculation and manageable through targeted interventions. Responding to misfortune in terms of risk requires individuals to take active steps to secure themselves, to act prudently and with foresight. Rose and Miller argue that responsabilisation, as a technique of 'government at a distance', , thus promotes mutual responsibility and reciprocal obligations in a 'new ethic of the active, choosing, responsible, autonomous individual obliged to be free, and to live life as if it were an outcome of choice' (2008: 18).

Such 'conducting of conduct' has been most telling in the field of health, where patients are increasingly urged to become active and responsible consumers of medical services and products (Rose 2007). The concept of responsabilisation in the context of HIV/AIDS interventions is built on a neoliberal 'logic of choice' (Mol 2008) in which complex issues are framed as simple matters of choice and where technologies and information are treated as neutral aids to making the right decisions. In this logic, patients are encouraged to become active participants in the quest for wellbeing and to take responsibility for their self-care, assuming that they have the capacity to do so. This takes place within a framework of an increasing pharmaceuticalisation of health (Biehl 2007): a shift away from a model of public health understood as prevention and clinical care towards an emphasis on access to pharmaceuticals.

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<sup>3</sup> The author agrees with Robins that the experience of being close to death is a powerful force for transformation and can lead to commitment to treatment adherence. In the future, however, this experience will hopefully become rarer, with antiretroviral treatment administered to patients before they reach a life-threatening stage of AIDS.

In contrast to the responsabilised self-empowerment proposed by Robins, critiques of contemporary biopolitics thus point to the disciplining features of liberal medical governance (Rose 2007; Miller and Rose 2008; Kistner 2009; Rose and Novas 2003), where the medical world demands a responsabilisation from outside with little understanding or appreciation of the real lives of the sufferers.

This paper argues that both these approaches to responsabilisation fail to explain the lived experiences of HIV/AIDS among people living with HIV/AIDS (PLHA) in Tanzania, who respond 'responsibly' to their condition but not necessarily in ways which are understood by the biomedical authorities. The promotion of individual responsibility for health becomes highly problematic in settings where disease rates are high, poverty is widespread, and access to state health care diminishing. Here, Lock and Nguyen argue, self-help groups have become 'vehicles for injecting ideas about personal responsibility for individual health in contexts where the notion that individuals can exercise control over their health is glaringly inappropriate' (Lock and Nguyen 2010: 28).

Susan Reynolds-Whyte reminds us of the dangers of focusing narrowly on biosociality among people who share the same biological condition, at the expense of considering the whole range of social relations that characterise and shape people's daily lives. She points out that these relations, as well as other concerns around the deeply unequal political and economic bases of health, may have an important impact on the formation of health identities and subjectivities. Ethnographic studies address these dangers by carefully analysing the formation of identity politics and new subjectivities in particular local worlds (Reynolds-Whyte 2009: 13). The people whose lives are portrayed here base their decisions on poverty and survival and reflect high levels of uncertainty about the real causes of HIV/AIDS. They are deemed responsible in relation to their life opportunities but may not be considered responsible in the eyes of those trying to control the pandemic within a strictly biomedical framework. Looking beyond the immediate biological consequences (failure to use safe sex methods leading to HIV infection, lack of antiretroviral treatment uptake and adherence to death from AIDS) and beyond biomedical rationality which places the preservation of individual biological life at the centre of its logic and interventions, this paper analyses people's choices and behaviours in the context of their lived realities. This repositions the notion of responsibility in the realm of the social and reveals the rationality behind apparently irrational practices.

### **Barriers to responsabilised citizenship in Tanzania**

In Tanzania, AIDS activism has not been able to mobilise widespread solidarity among HIV-positive people or rally much public support to provide the supportive environment which Robins (2005a, 2005b) regards as essential for an empowering

transformation of subjectivities into responsabilised citizen-clients. Rather, AIDS support groups in Tanzania are fragmented and characterised by relations of patronage, with pervasive donor dependency leading to factionalism and infighting, rather than empowering solidarity and sense of belonging (Beckmann and Bujra 2010: 1048, 1057). Treatment testimonies are here largely viewed as a source of income and are thus highly contested, losing much of their transformational potential (Beckmann 2010). The transformations of HIV-positive people's subjectivities, which Robins describes for the South African case, where PLHA have turned stigma into a 'badge of pride' (2005a: 3), are limited to few long-term AIDS activists rather than describing a turn in a wider PLHA community in Tanzania. In the on-going presence of HIV/AIDS-related stigma, many see antiretroviral treatment as an opportunity to hide their HIV status in order to avoid stigma (Beckmann and Bujra 2010). Biosociality here responds to the immediate needs of those who have no recourse to other support networks, rather than forming the basis of a larger rights-based movement.

Moreover, the biomedical system is strongly hierarchical, with medical professionals carefully guarding their expert knowledge. Patients are generally regarded as ignorant and irrational, in need of being educated and disciplined through counselling and education sessions that repeat standard scripts of managing their conditions through 'living positively'. This includes embracing their HIV-positive identity, following the doctor's advice, and striving to be morally good people who neither drink nor smoke nor engage in illicit sex, and who help fellow sufferers through home-based care and peer counselling. The disciplinary – and, ironically, *disempowering* – nature of the production of treatment adherence is an intrinsic feature of AIDS treatment programmes (Mattes 2011), whose goal it is to create obedient patients who uncritically submit to whichever treatment is administered but who are active in their self-care. Doctors here rarely see patients as partners in diagnosis and treatment. Patients, in turn, are hardly scientifically knowledgeable, rights-bearing partners in their health care, nor do they expect to play an active role in their interaction with the biomedical system.

Patients are acutely aware of their dependence on the goodwill of doctors and nurses, which has been heightened by the provision of free antiretroviral treatment. This dependency has stifled the emergence of empowered patients and silenced the voices of activists. The research participants recognised the potential danger of engaging in confrontational activism. 'You're not beaten or arrested,' a female leader of a support group in Dar es Salaam explains,

but the danger is to be despised (*kuchukiwa*): the hospital staff are the ones who will have to care for you when you get sick. So you better not upset them. Especially if you're hospitalised it's really bad: they just put you on tranquilizers and watch you die. Nurses steal the medication you bought and sell them off again, because you can't leave the

medicines at your bedside, you have to give them to the nurse to keep and administer them. (Interview, 29 May 2008)

Several research participants reported fear that the doctors could keep the ARVs from them if they appeared too critical: 'they will pretend that they have run out of drugs and just send you home. What are you going to do? You can't prove that they actually have them in stock.'

This fear is closely connected to concerns over immediate survival, since it is widely believed that the decision to start antiretroviral treatment should not be taken lightly; the constant and urgent warnings on the adverse effects of lax adherence in adherence counselling and in the media led to rumours that the discontinuation of the treatment would lead to a rapid and forceful return of AIDS and kill the person quickly. Despite these fears about the dangers of stopping treatment, some patients do not adhere satisfactorily, for reasons including side effects, food scarcity, household politics, and competing aetiologies (Beckmann 2012: 696-705).

Even in those cases where commitment to biomedically responsible lifestyles and treatment adherence is strong, this commitment may not last forever. As individual morbidity ebbs and surges, as new models of explanation and treatment appear and old ones are discarded, and as phases and situations in life change, so do people change their minds, try different approaches, abandon others, and many never give up seeking the one thing that biomedicine cannot offer: a cure. These dynamics point to the processual nature of illness, which is particularly pronounced in the case of HIV/AIDS, due to its long, drawn out progression from asymptomatic infection to the various different symptoms of AIDS changing over the course of years. The specific characteristics of HIV/AIDS, the many different faces it shows, open a wide frame of uncertainty (Whyte 1997) and allow for changing positions taken by the actors involved, thereby re-constituting the relationships between the sick person and their social environment.

Peter, a 30 year old man from Dar es Salaam, is highly 'treatment literate', having read widely about the workings of the HI-virus and antiretroviral drugs in the body. He had been close to death when the new treatment became available and has since recovered quickly. He describes his experience of ART as revelatory:

'the drugs, they change the system of your whole body. When I started to take them, I could feel that they went straight into my brain; when I leant my head to the wall it felt like my brain was directly touching the wall, like it was naked. Then I realised that the drugs really change your whole system. They go into the brain, the kidneys, the blood, everywhere. They keep down the viral load and protect the CD4 cells and the white blood cells. And you get so hungry. Shortly after starting the treatment I noticed that my stomach had swollen. At first I thought I had a problem, but then I realised that the drugs had already started to change my body, so that every food I eat now stays in the body and re-builds the body, there is no food that goes unused (*hakikai pembeni*).'

Peter is in many ways a model patient-citizen, who educates others and serves as an example. He had integrated scientific information on the drugs and the virus into his lay understanding of his condition and views the drugs as his lifeline – without them he would be dead. He scolds others who are lax in their adherence and gets angry when people voice their thoughts on stopping the treatment.

After some months, however, his position changes. His efforts to gain an income through the ‘AIDS industry’ by running a small HIV/AIDS support group have failed and he fears for his possibilities in the already tight labour market if people would find out that he is HIV-positive. ‘They think you are sick and won’t give you work,’ he complains. The risks of disclosure that HIV advocacy entails, he feels, are too high, and the jealousy caused by competition for donor funding is too risky in an environment where survival rests on functioning social relationships. At the same time, the pressure of hiding his infection and relying on his sister for maintenance is becoming more difficult to handle every day. Peter joins a Pentecostal church and starts training to become a pastor. After unsuccessfully trying to survive through AIDS activism, he finds that the church offers both a supportive environment that recognises the hardships of contemporary urban life<sup>4</sup> and a possibility of making a living. He starts talking about cases where *damu ya yesu* (prayers, lit. ‘the blood of Jesus’) cured AIDS patients. ‘One day I will leave the ARVs behind,’ he says.

Peter’s case shows that the biomedical explanation is appealing in the beginning, when it brings a swift recovery from an almost fatal condition. This experience often starts to wear off when the immediate health crisis is overcome and the patient’s health is restored. In the course of recovery, it is argued, the patient turns back into a person again, and many at this stage try to shed, rather than embrace, their HIV-positive identity. Only few had managed to carve out a living as AIDS activists. Most were eager to go back to a ‘normal’ life, seeking employment or setting up a small business, remarrying, and having children. Many regarded their HIV identity as impeding this process. Mohammed, for example, a builder in his late thirties, valued the ARVs for restoring his health and enabling him to hide his infection, thus starting new employment untarnished by the stigma of HIV. Mariam, too, preferred to keep her infection confidential when she acquired some land to farm vegetables for sale in the market: ‘People won’t buy if they know you have AIDS,’ she says. Even the search for a marriage partner has changed over the past few years. Initially, many joined a support group in the hope of meeting a new spouse, and indeed many married a group member, especially in Zanzibar. But few of these unions lasted, due to affairs and jealousies within the group. Recently, an increasing number of members are seeking marriage partners outside their support group – either among new HIV clinic attendants *before*

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<sup>4</sup> Dilger (2007) highlights how Pentecostal churches offer a community of social and spiritual solidarity and support in times of need, as well as a perspective that allows members to make sense and act upon the social transformations brought about by globalization and modernity.



these could join a group, or even entirely outside the 'HIV realm,' through traditional channels of match-making. These and many other examples suggest that the transformation the research participants most strove for was a transformation from patient back into a 'normal' person, rather than from patient to empowered patient-citizen.

While ARVs can facilitate the process of re-establishing normality in life, they may also be experienced as uncomfortable and even harmful. When the long-term side effects of the drugs become visible, this often leads to increased dissatisfaction with the treatment, and some consider dropping out. Liver and kidney problems, elevated blood pressure, and numbness of the limbs due to lasting nerve damage are constant reminders of the persistent presence of the virus, of the fact that life on ARVs is merely a borrowed life. The visible side effects of ART, such as skin discolouring, hair loss and lipodystrophy are particularly undesirable as outside markers of sickness. In a society where the ideal female body is characterised by a large bottom and small breasts and belly, these common side effects are especially devastating for women, and considering that many of the HIV-positive research participants relied on transactional sex for an income, these conditions may also be economically detrimental. While clinic staff and patients often frame treatment success in terms of restoring 'beauty' – '*umependeza*, you look attractive,' doctors and friends exclaim when a patient gains weight and their skin lesions heal – women often secretly complain about the long-term changes in physical appearance: '*Sipendezi*, I'm not attractive anymore,' remarked a young woman, to nods of agreement among the other women also waiting in the treatment queue. 'Look at my fat belly and big breasts! Men don't like that.'

Adherence counselling and advice by doctors and nurses cannot adequately address these concerns. Clinic staff are frequently overburdened and lack the time, skill and resources to respond to their patients' difficult dilemmas. Counselling thus largely takes the form of repetitive scripts of positive living, stressing the importance of adhering to treatment at all cost and highlighting the dangers of failure. This form of counselling only vaguely resembles the process of 'informing' that neoliberal health discourses of consumer choice equate with patient empowerment by transferring objective biomedical information to the patient who can then make a rational and informed choice. In this discourse, Mol (2008) argues, scientific information is regarded as a growing collection of facts that lead to an increase in certainty. When translated into health information, medical knowledge is thus transformed and turns into a technology of compliance rather than a source of empowerment. Henwood et al. demonstrate how the pressure to become healthier and informed often leads not to a clear choice, but to confusion and anxiety (2011: 2030). Rather than responding with care, the constant warning to be 'good' patients and make the right choices – to eat healthy food, abstain from sex, avoid pregnancy, etc. – adds to the pressures and confusion patients already face and shifts the blame for treatment failure onto the patients' shoulders.

However, this process is not necessarily entirely disciplinary. Fully aware that their real-life problems cannot be solved, staff and patients engage in exercises of ‘reminding each other’ (*kukumbushana*) of the benefits and rules of living with HIV and ARVs, often in an amicable manner. In the IDC<sup>5</sup> clinic in Dar es Salaam, for example, one nurse joins the waiting queues for treatment and offers advice. Some of the patients are too shy to speak up, but the nurse tries to make them feel comfortable. ‘I’m here to help’, she says, and jokes with some of the more outspoken patients she recognises, to loosen the mood: ‘How do you cope with not drinking? I know you like your beer!’ she asks one of the older men, who grins when the others laugh. For a brief moment, a sense of light-heartedness sparks up. ‘Do these people look sick?’ she asks. ‘No, we aren’t sick’, some patients respond cheerfully. She then goes on to ‘teach’ patients about the importance of not drinking, of turning up in time for their clinic appointments, and of taking their drugs, despite her knowledge that many will not be able to adhere to the strict regimens. But through this brief interaction she has achieved something just as important: to give hope to those new in the queues for treatment, those who are sick and have lost hope, showing them that there is a future, a light – and even laughter – at the end of the tunnel. Aware of the limits of her capacity to change people’s structural hardships, in this short instance she acts within what Mol calls a ‘logic of care,’ a concept which will be revisited below. But first let us take a closer look at the process of responsabilisation.

### **Forms of responsibility**

Peter’s story raises important questions around the production of knowledge and truth, the definition of expertise and a dominant discourse. Ultimately, these are questions about power: who defines where HIV/AIDS comes from, what the real causes of a person’s suffering, and thus the best treatments and strategies for prevention are? At the global level of development programmes and health finance instruments, these definitions have been framed within the parameters of scientific rationality, focusing on substances circulating within and between individuals’ bodies; virological explanations, barrier methods and behaviour change, and pharmaceutical treatments guide global institutions’ and national governments’ approaches in managing HIV/AIDS. These form the basis on which a hegemonic definition of *biomedical* responsibility has been formed, designed by experts at the global level to be internalised by local patients and promoted through large-scale information and education campaigns and voluntary and compulsory instruction within institutional settings, including schools, clinics, and hospitals. Based on notions of risk management and rational actor models, they assume that once educated, individuals would adjust their actions following the newly acquired

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<sup>5</sup> The Infectious Disease Centre clinic, located opposite the main train station, provides STI and HIV/AIDS testing and treatment services, including paediatric care, and tuberculosis (TB) vaccination for AIDS patients as part of a collaborative TB vaccine research programme run by Muhimbili University and the Dartmouth Health Project from 2001 to 2008.

scientific insights. Failure to comply with these measures is judged as an indicator of the individual's ignorance and irrationality, and as a counter measure a higher grade of information is recommended (cf. Mattes 2011). While Robins (2005a, 2005b) highlights the empowering changes of TAC activists' subjectivities that led to their transformation into responsabilised active citizens, ultimately the framework for responsabilisation is set through scientific reasoning and biomedical experts based on a logic of choice. Within this logic, the ultimate value of life is biological, for which social life may need to be sacrificed. Empowerment here means being empowered to act according to biomedical treatment regimens and recommendations. Responsibility is conflated with biological rationality, thus adding a moral dimension to the way people's actions are perceived.

Viewed in this light, the notion of responsabilised HIV-positive citizens is reminiscent of earlier debates around risk that highlight the disciplinary nature of approaches to risk management (Day 2000; Caplan 2000), which originate from mathematics and game theory. Risk presumes the measurability of hazards and the ability to avoid these through responsible behaviour. But Lock and Nguyen point out that for the individual, far from providing certainty, risk categories produce uncertainty. Contrary to divinatory technologies which warn of unfortunate events by contextualising them in the client's life circumstances, resulting in highly individualised predictions, population-derived epidemiological forecasts produce decontextualized probabilities: they predict how many will die within a group of people, but not who will die (Lock and Nguyen 2010: 26). Recognising risk and responsabilisation as part of governmentality (Foucault 1991), a form of self-government where avoiding risk becomes a moral enterprise related to issues of self-control, self-improvement, and self-knowledge, provides insights into the ways existing power structures are maintained. Presented as a practice of freedom, giving the individual the opportunity to choose the conduct of their lives in a context in which notions of selfhood privilege the empowered, autonomous self, can barely conceal that this is a form of shifting responsibility onto the individual (Caplan 2000: 11; Dilger 2012: 66), which coincides with neoliberal reforms working in the same vein.

Biomedical approaches to AIDS assume that the matter of utmost importance for everybody involved must be to contain and manage the virus, which requires the precedence of biomedical rationalities over all other rationalities. This view privileges physical life over social life. But life-as-it-is-lived must be embedded in local social and moral worlds; it requires intersubjectivity, sharing with others, social belonging, dignity and respect (Marsland and Prince 2012; Mattes 2012). While life made possible by pharmaceutical regimes ensures the survival of individual bodies, the research participants desired a meaningful life as persons, as social and moral beings.

Moreover, individuals are not always guided by self-interest and forces that are under their control; Dilger (2012) and Mattes (2012) show how decision-making in the realm of HIV/AIDS is shaped by the individual's socio-economic, cultural and political environment and by rules governing moral behaviour. The collective backdrop of life in

Tanzania is a pervasive sense of uncertainty – of daily survival, of the causes of the suffering that has taken hold of the country, and of the best ways to protect oneself and ones' loved ones from it. HIV/AIDS here is only one among a variety of threats people must face, and biomedicine only one among several models of explaining and managing illness. Many reported a sense of powerlessness when talking about HIV/AIDS, and expressed their way of facing the threat by falling back on concepts of fate and trust in divine power.

Presupposing some sense of certainty, notions of risk and responsabilisation assume the existence of an ultimate truth to be converted into a 'right' set of behaviours. However, as Fassin (2007) demonstrates in his analysis of the South African government's past endorsement of AIDS dissident theories, biomedical knowledge itself is not as immutable and certain as it is portrayed to patients: as scientific knowledge evolves, old insights are proven wrong and discarded, replaced by new findings sometimes contrary to those declared previously. Indeed, this capacity to be critical and reactive forms the basis of scientific activity. Fassin points out that a specific feature of *biomedicine*, however, is that it 'has effects on persons and on society through diagnoses and treatments, through individual counselling and collective pronouncements, through the production of norms (...) Thus, contrary to science, when biomedicine speaks the truth it also speaks morals and, in doing so, becomes socially vulnerable' (Fassin 2007: 84). In the process of translating new scientific findings into truths put out into the public arena, complex research results are simplified, cautious tendencies are asserted as certainties, and past stances are blocked out of the biomedical establishment's memory – but not forgotten by the public (ibid: 85). Following Fassin, this paper argues that this absence of biomedicine's memory of its past mistakes and revisions of opinion has created uncertainty about the reliability of scientific information and combines with conspiracy theories about the hidden motives behind medical interventions. The controversies around the potential harm and benefits of nevirapine to prevent mother-to-child transmission of HIV in South Africa are a prime example (ibid: 81-2). More recently, education on condoms is being watered down by latest studies that show it is safe to drop condom use for couples on ARVs where both partners' viral levels are undetectable. There are few clear messages in the field of AIDS, no unequivocal agreements, no clearly drawn enemy lines. In Tanzania, biomedical explanations of HIV/AIDS co-exist alongside explanations that attribute its symptoms to witchcraft, ritual pollution, or divine retribution for immorality, all with very different consequences for prevention and treatment strategies. Uncertainty is what prevails, both within the medical realm and within the wider discourses about HIV/AIDS.

In such contexts of material and epistemological uncertainty, the focus on responsabilisation and choice in the management of HIV/AIDS precludes recognising the fact that people actually try to act responsibly and make informed decisions, and that they do this by taking into account their socio-cultural, economic, political and

biological context. In the absence of one definite truth, people carefully weigh their own past experiences and those of others, the doctors', religious leaders', traditional healers', and international aid workers' advice, talk in the streets, social expectations and the structural forces that set the bounds for their actions. The danger of the logic of choice and the concept of the responsabilised citizen is that it once more allows for failure to be attributed to the patient for making the wrong choices. It underlines persistent ideas about Africans as irresponsible and irrational and absolves interventions planners and policy makers when programmes fail. The following case study shows how people come to make decisions that are biomedically irresponsible, but make sense and indeed express their social responsibility.

### **Neema: structural factors once more**

The author met Neema, a 31 year old woman from Dar es Salaam, regularly at the HIV clinic where she collects her ARVs every month. She is a single mother of three, having left her husband because he failed to provide for her and their children. Unable to claim her right to financial support from her husband, she started work in a bar. 'My husband never loved me,' she says. 'He has a business and a lot of money, but he doesn't help me at all. He even agrees to let me work in a bar, you see?'<sup>6</sup> In Kiswahili, the term *baamedi* (barmaid) is synonymous with 'sex worker,' but Neema is adamant she only sells beer to customers. But now she has to pay rent for her room and buy food and clothing; her salary of TSH 50.000 per month does not even remotely cover her expenses. She concedes that she needs a man to help. She considered marrying again, but men who are willing and able to provide for a whole family are rare.

After some time she says: 'when the *wageni wa mkoani* (travellers from outside Dar) come they give me TSH 10.000, 15.000, sometimes even 20.000 if I go with them, so I do it.' 'But I do protect myself,' she quickly adds, aware of the script on safe sex she is supposed to follow, 'I always use condoms.' Later, however, the author sees her sneaking into the STD consultation room. Slipping back into the queue of people in the waiting area she whispers that she has an STD: *nawasha chini, sehemu ya siri, natoka vipete*, 'I itch down there, in the secret place [i.e. the genitals], and I have pustules'. The doctor gave her an injection and cream which she had to buy for TSH 20.000. She says:

ever since I've got this job I don't have problems anymore. The children eat and dress well, go to school and I can buy the medicines I need. I don't have any worries anymore. Without the job, do you think I would have been able to buy those drugs now? *Maisha magumu* – life is tough. (Field notes, summer 2008)

Neema's story, which mirrors those of many of the research participants, illustrates the pressures of the daily fight for survival and the vulnerabilities and lack of choice in

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<sup>6</sup> Field notes on a number of conversations with Neema in the summer of 2008.

contexts of structural violence (Farmer 1992). Neema was aware of the fact that she should not be working in the sex industry because she could infect others, and indeed she had not disclosed her HIV status to anybody other than her sister. Everybody would scold her, she says, and if they found out at work she would lose her job. Her story also points to the impact of pervasive gender inequalities on the control of HIV/AIDS (Haram 2005): Neema did not feel it was her responsibility to protect her customers from infection – after all they played the more powerful part in their relationship. They chose to have sex with her, while she was forced into this work. She did not like the job and complained that it made her tired, but she was proud of being able to provide for her family and not having to beg the relatives for help. She took on the responsibility of caring for her family, at great sacrifice to herself. Even in health terms, she thought the work was helpful: worrying (*kuwaza*) is regarded a major reason for falling CD4 counts and deteriorating health. An integral part of positive living includes the ability to acquire a calm state of mind and eliminate those circumstances that would cause worry. By taking away the worries about immediate survival, for a while Neema felt her job helped her to become healthier, and the money she earned even allowed her to buy fruit and vegetables. Yet, after some months the work started to take its toll, and she complained about aches and rashes. Lacking any other means of income, however, she could not afford to stop.

Framing Neema's behaviour within a logic of choice ignores the fact that she actually had little choice and serves to add tropes of blame and guilt to the numerous pressures she already faces. Ironically, it could be argued that Neema's actions fit well within a neoliberal order. Employing a pragmatic approach, she weighs her alternatives and chooses those that seem to maximise her profits, by looking after herself and those close to her. After all, why should somebody in her position, at the bottom of the ladder, be altruistic? Neema's story, exemplary of many women left to fend for themselves after disclosing their HIV status to their partners, shows that antiretroviral treatment alone cannot solve the HIV/AIDS pandemic. Presenting the complexities of her life as an HIV-positive single mother in an urban environment as a simple matter of choice reflects an individualised, atomised view of social life that ignores the ways people's lives are embedded in an intricate web of relationships. Without a more supportive environment, the pharmaceuticalisation of health is likely to create situations in which information replaces care, and patients' failure to follow biomedical health advice leads to new patterns of blame and exclusion of those who cannot easily slip into a model of therapeutic partnership (Biehl 2007).

## **Conclusion**

Two rather different concepts of crisis play into the management of HIV/AIDS discussed in this paper. The rhetoric of crisis as an accelerating emergency of an AIDS pandemic presents crisis as a *rupture* that simultaneously highlights and dispenses time: it forces

us to inhabit the present and act immediately. In this way, Redfield argues in his analysis of the politics of life in humanitarian aid programmes, 'crisis is the most pure environment for a technician, where expertise can and clearly must engage with the immanence of problems' (2005: 346). As such, the rhetoric of crisis has facilitated an unprecedented mobilisation of resources for the creation of vertical mass-HIV-intervention programmes. Based on technical approaches and a logic of choice, these interventions serve as channels for mainstreaming biomedical rationalities and neoliberal notions of responsabilisation and self-care. When this mode of suspended time is extended into an ongoing state of exception, attention to dignity and the social and moral facets of life can be deferred, while the preservation of physical existence takes centre-stage (ibid: 346). This is one of the unintended consequences of HIV intervention programmes that run in crisis mode. Geared to radically transform subjectivities and bodily practices, they promote the concept of an individual self whose focal point of reference is its own biological life and a corresponding concern for others' biological lives. The programmes encourage altruism in 'saving' others, while at the same time highlighting the need to 'save yourself' through technologies of the self. As 'governmentalities directed at the biological existence of those living with or at risk for HIV' (Nguyen 2009: 213), AIDS programme planners insist that the appropriate level of intervention is biological: the saving of lives, rather than ensuring livelihoods. The notion of humanity produced here is 'one akin to Agamben's *zoe*, or "bare life" (1998)' (quoted in Kalofonos 2010: 375).

However, this paper shows that even under the most adverse conditions, people maintain and are guided by a tenacious connection to socially meaningful life, embedded in webs of social relations. This social embeddedness becomes ever more important in the Tanzanian setting, which is characterised by a form of crisis as *context*: the research participants were in a constant state of material and spiritual crisis, trying to get by and make sense of competing messages and demands – not always successfully, but generally by negotiating different forms of responsibility, in a constant quest for some sense of security in the face of deep uncertainty.

A focus on responsabilisation glosses over these alternative forms of responsibility and places an undue burden on people who are barely able to survive. It also helps to mainstream the fragmented and unfinished nature of biomedical knowledge, through the simplification of research results in the biomedical production of knowledge.

In the logic of choice, complex problems are reduced to simple matters of choice, aided by information and technologies. Following Mol, this paper proposes that an alternative logic, the 'logic of care,' is better suited to capture the full picture of how care is (or should be) practiced. In this logic, information and care are intertwined and attend to a complex set of specific emotional and care needs. Good care means providing emotional support in the context of uncertainty and anxiety and disentangling the practicalities the patient has to deal with in finding ways to make life more bearable. Rather than moralising and judging the patient, the logic of care aims to mutually adjust technology,

everyday habits and constraints, people's skills and propensities, and their social environments (Mol 2008: 52-3).

Would good care have influenced Neema's sexual behaviour, or Peter's decision to stop ART? Perhaps. It would be specific and situational, it would listen attentively to their struggles to survive and their grievances with the AIDS industry, it would take their family situations and religious beliefs and aspirations into account, and look for a way forward, rather than measuring guilt and allocating blame. Programmes that run in crisis mode cannot attend to these matters.

Despite the obvious limitations, there are attempts in some HIV clinics to attend to the care needs of patients. Local HIV clinic staff on average were much better than other hospital departments in building rapport with their patients and creating a comforting atmosphere. They often recognise the multiple demands on patients from different parts of their social networks and mediate in situations of conflict. They conduct follow-up visits and talk in ways that are meaningful to patients, e.g. by employing local sheikhs and using religious arguments. Such spaces for close social and moral engagement with patients are important features of a supportive care environment, but their existence is constantly threatened by chronic overburdening of clinic staff and lack of funds.

Unfortunately, with global HIV funding currently flat-lining and likely to drop in the near future, the rhetoric of crisis regains power and many local care initiatives have fallen through. In order to keep patients on treatment, the need for individuals' commitments once more becomes an urgent matter: since costs of second- and third-line treatments are still prohibitively high, drug resistance must be stalled through strict treatment adherence, and new infections must be avoided. At the same time, the money dedicated to fund social support staff, food supplements, home visits, and the involvement of religious leaders is increasingly invested in drugs in an intensifying pharmaceuticalisation of health which is geared towards 'saving lives.' This is the measure of success that programmes need to present to donors to justify the value of their efforts. While activist movements continuously lobby for a right to treatment, in practice health is increasingly treated as a form of charity, demanding if not gratefulness, then at least a responsible and dutiful use of the donor community's extensive investments. But despite huge investments in the fight against AIDS, resources are insufficient to tackle the root causes of the problem or provide appropriate care. As seen in the Tanzanian example but reiterated in many low-income countries, treatment programmes constantly struggle with resource shortages and more often than not fail to provide comprehensive care. This 'partial care' practice based on a logic of choice not only threatens the success and sustainability of HIV programmes, but also the wider credibility of biomedicine in the area; already, hospitals' reputation is tarnished in the eyes of patients by the experience of sub-standard care, corruption, and lack of compassion. Recent shifts in global health discourses away from vertical health



interventions to broader health issues and health systems strengthening are first promising steps in the right direction, but do not go far enough.

Without wanting to dismiss the importance of facilitating survival through technical means such as antiretroviral treatment, there is a need to caution against the potential implications of the notions of responsabilisation. Rather than calling for responsabilised citizens who make scientifically informed and rational choices, an important task for anthropologists must remain 'finding zoë amid the bios' (Redfield 2005: 348).

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