The commodification of misery:
Markets for healing, markets for sickness

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Abstract The opening up of the healthcare sector to privatisation in Zanzibar has resulted in a process of marketization that captures both biomedical and non-biomedical forms of healing. The emerging market for health has created opportunities for some, but is increasingly closing off routes for treatment for those who cannot afford the rising costs. This shift in focus from healthcare provision to profit-making, it is argued, promotes emotional distancing and the disintegration of care relationships that used to be structured by moral responsibilities. The transgressive processes of commodification have become particularly visible in the global ‘fight against HIV/AIDS’, where an industry is emerging in which the very state of ‘being sick’ can become a commodity. Feeding donors’ demands for participation in a rights-based agenda of ‘making the voices of the afflicted heard’, HIV-positive people are joining the bottom rung of the AIDS industry. This commodification of people’s misery in the form of treatment testimonies and illness narratives is the epitome of marketization in a world in which an infected body assumes a market value and suffering becomes a way of surviving.

The last decades have seen the large-scale ideological and financial promotion of biomedical rationality and an increasing shift in responsibility for health and well-being onto the individual. In Zanzibar, as elsewhere, neoliberal reform packages have pushed for the state’s withdrawal from the provision of healthcare and other social services and the introduction of privatization and cost-sharing models, and a relatively new consumerist and entrepreneurial dimension in the provision of healthcare (Parkin 2006: 713). These trends have led to an increasing need for cash in the quest for well-being and care and have created the opportunity for some to make considerable profits. This raises new questions around commodification and the creation of markets in areas that used to be structured by moral responsibilities and kinship relations rather than economic opportunity and profit.

HIV/AIDS has highlighted an increasing dehumanization of affect, emotion and care, as has been shown in a number of studies investigating how social support networks break down under the burden of the disease. The stigma related to HIV/AIDS is one reason for the disintegration of care relationships and emotional distancing; and the high cost involved in caring for a chronically ill person – or several, as often more than one family member is infected – is another. I argue that this breakdown of social and emotional support is indicative of a broader process of commodification that is emerging in other areas of treatment and care-giving too. It captures hospital wards and clinics where quality care is often only provided upon the payment of cash, as well as non-biomedical practitioners who have started to view their services as a marketable commodity. These emerging markets for health and well-being are resulting in increased competition among a range of different healing practices and practitioners,

and to progressively less access to treatment options for patients who lack financial resources.

Commodification processes are particularly visible surrounding HIV/AIDS, which has become a lucrative business. With vast amounts of money invested in the ‘fight against HIV/AIDS’, an industry has emerged that is providing new market opportunities for a range of actors from the global to the local. Simultaneously, it painfully illustrates the constraints faced by the poor and marginalized who see that donors are often more interested in physical, countable lives (‘our investment in antiretrovirals/information and education/condom distribution saved x number of lives last year’) than in livelihoods, and in ‘AIDS victims’ rather than persons who need to survive both physically and socially.

In this industry, the very state of ‘being sick’ can become a commodity and a source of income. Afflicted with a deadly disease, faced with the loss of jobs, friends and support networks, many of my HIV-positive research participants had nothing but their sick bodies as a resource. Feeding donors’ demands for PLHA (People Living with HIV/AIDS) participation in a rights-based agenda of ‘making the voices of the afflicted heard’, they are joining the bottom rung of the AIDS industry, using their sick bodies and PLHA identities as a ‘commodity of last resort’ (Schepers-Hughes 2002: 2). In such contexts, commodification becomes highly transgressive and can pose serious risks.

This chapter follows the processes of commodification of well-being and misery in Zanzibar that are particularly apparent in the management of HIV/AIDS. It starts with a discussion of the general deterioration and privatization of Zanzibar’s health services, and the ensuing emergence of a market for health and well-being that goes beyond biomedical services and increasingly includes ‘traditional’ healing, thus shifting the focus from healthcare provision to profit-making. The devastating impact of these processes on the provision of care for impoverished HIV-positive people whose support networks often crumble under the emotional and financial cost of the infection is then explored. The final sections analyze their efforts to build alternative social networks by joining PLHA support groups and highlight the precarious nature of their participation in the AIDS industry, which frequently exacerbates their already vulnerable situation. The commodification of people’s misery in the form of treatment testimonies and illness narratives is the epitome of marketization in a world in which an infected body assumes a market value and suffering becomes a means of survival. The chapter concludes with an analysis of the strategies HIV-positive people use to negotiate a fragile balance between global discourses on openness and disclosure and living with a highly stigmatizing infection.

The findings presented here are based on twenty-two months of ethnographic fieldwork on living with HIV/AIDS in Zanzibar that was undertaken in 2004-2005 and during several follow-up visits in 2007 and 2008. Using mainly participant observation, I lived with a local family and worked closely with a group of HIV-positive people who had formed a support group, the Zanzibar Association for People living with HIV/AIDS (ZAPHA+). I spent my days in the ZAPHA+ office, accompanied ZAPHA+ members as well as my friends and my host family on visits to hospitals, healers and midwives, visited people in their homes, took part in AIDS- and health-related education sessions, policy planning and monitoring meetings by a range of NGOs and development organizations, and participated in daily life on the islands.
Emerging markets for health in Zanzibar

Zanzibar is a small island archipelago off the Tanzanian coast with a predominantly Muslim population. Formerly an important trading post, it has a long history of trade and migration across the Indian Ocean. Zanzibar’s golden days of economic success are long gone and the economic situation today is extremely fragile. A legacy of extensive plantation agriculture, the socialist policy of isolation and self-reliance from 1964 to the mid-1980s and the neo-liberal reforms of the late 1980s/early 1990s with their thriving corruption and recurrent political turmoil have created an environment of instability and economic fragility combined with a profound lack of state-sponsored social-security services.

After the 1964 revolution, the new socialist government heavily promoted biomedicine in Zanzibar and proclaimed a commitment to free and universal biomedical healthcare. At the same time, practitioners of non-biomedical diagnostic and healing techniques were regarded as backward and their methods as being based on ‘superstition’ and thus not fit for a socialist society. As a consequence, many were forced to flee the islands (Parkin 2006: 698). However, the commitment to provide free healthcare for all proved impossible to fulfil, and these policies ushered in an era in which neither biomedical nor traditional treatments were easily accessible. The biomedical health system – formerly in much better shape in Zanzibar than on the mainland – started to deteriorate in 1970 when the government banned private medical practices. Subsequently, patients had to wait for treatment at government hospitals and clinics for days or go to Dar es Salaam for treatment (Martin 1978: 60).

After two decades of economic and political isolation, the socialist experiment was abolished, resulting in a de facto return to capitalism and political liberation in the mid-1980s, which has enabled the return of private practitioners, pharmacies and small hospitals. Traditional Muslim Zanzibari healers have also started to practise more openly again (Parkin 2006: 699).

The neoliberal move towards the privatization of public services in the past two decades has included the health sector, and cost-sharing models for public health facilities have been introduced. Patients now have to pay a hospital admission fee, buy many of the drugs they are prescribed themselves, and cover the costs of surgery and other procedures, often on top of the bribes they had to offer in many of their encounters with the health system before. While medicines and services were often simply not available in socialist times, the increase of private-sector health provision on the islands has meant that the problem has shifted from availability to accessibility: better-quality healthcare is in reach although most struggle – and fail – to afford it. The two accounts that follow show the precarious position people are faced with should

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2 These are often labelled as ‘traditional’ healing. While some of the practices indeed go back to long-standing local aetiologies and therapies, new practices are constantly being developed and imported. Zanzibar, with its long history of migration and cosmopolitanism, is prone to the import and mixing of new approaches, and healers are often sought precisely because their origins are outside the islands.

3 While officially the under-fives, pregnant women, the disabled, and HIV/AIDS patients are exempt from the health fee, my HIV-positive research participants complained that this rule only seemed to apply when they sought treatment at the HIV clinic. When referred to another department, fees were usually incurred.

4 Roughly Tsh 70,000 to Tsh 100,000 for routine surgery, such as a cesarean section in 2007 (the exchange rate was US$ 1 = Tsh 1,457 on 22 June 2010.) In middle-class private hospitals in Dar es Salaam, these cost between Tsh 1.5m and Tsh 2.5m in 2010 (Daily News 2010).

5 This is true for the majority of the population but excludes the elite who had access to preferential treatment and a VIP ward in the hospital with private rooms and better service. These VIP rooms are available for those who can afford the extra charges.
they need medical care. The first captures the situation in a ward in Mnazi Mmoja, the islands’ referral hospital.

In August 2008, my long-term informant and friend Zakia\(^6\) was hospitalized with final-stage AIDS. Apart from 18 occupied beds, the ward was empty and lacked mosquito nets, sheets and pillows; and everything was very dirty. Zakia’s parents mobilized all their resources to buy the intravenous fluids and medicines that the doctor had prescribed to prepare Zakia’s weak body for the start of antiretroviral treatment. Yet after six days in hospital, her IV drips were still sitting on her bedside table and her dressings had not been changed and were yellow with pus.\(^7\) The only diagnosis she had received was ‘stomach problems’. In the mornings, a nurse came in to sweep the floor but did not clean the tables or wash the patients. Even when asked for help many of the nurses did not react but became angry and mean. None of the people visiting Zakia – family and fellow activists from ZAPHA+ – were able to get the nurse to fix the drip, and they could not afford to pay her to ‘ease’ the service. Zakia’s friend came in every day to care for her, take her to the toilet, and wash and feed her. The woman in the next bed, also suffering from AIDS, had nobody to look after her. A family member came once a day to bring a plate of food but nobody took the time to feed her. Too weak to eat herself and abandoned by her personal networks, she was left on her own.

The poor quality of services in Zanzibar’s public health facilities is not only due to a constant scarcity of basic equipment and drugs and a severe shortage of clinicians but also to what seems to be increasing indifference among staff towards their patients. Several of the older nurses complained that trainee nurses often joined the programme not because they liked the profession but because they had connections with the authorities. In addition, Structural Adjustment Programmes have led to rapidly decreasing salaries for public-sector employees (Dilger 2010: 103), who generally need to have several jobs to make a living. The opportunities offered in the private healthcare sector mean that increasingly doctors are starting their own private practices to which they devote much of their time and energy, reducing their hours at the public hospital to the bare minimum. Nurses equally try to supplement or replace their meagre public-sector incomes, for example with work in foreign health development projects. The impact of such trends on the provision of care in emergency situations is highlighted in the following account from the same hospital.

A woman from a village on the east coast who was obviously in pain was rushed by ambulance to the maternity ward. This was the first time I had ever see the hospital ambulance in operation. She had been in labour for almost three days, her relatives said, but the birth was not proceeding. She was admitted to the ward but shortly afterwards the doctor came out and told them that she needed an urgent caesarean section and that they should find Tsh 70,000 to cover the operation. The relatives rushed off to mobilize the money and I heard other people talking about another woman who had been in hospital since the day before waiting for a C-section, but her family could not pay for it. This delaying strategy was obviously dangerous for both the mother’s and the baby’s health. While the woman did receive the surgery some hours later, the doctors

\(^6\) All informants’ names are anonymized, except those who are openly HIV-positive and assume publicly visible roles in ZAPHA+.

\(^7\) Hygiene standards were generally extremely poor, which resulted in widespread bacterial co-infections in patients. According to the Health Information Bulletin 2008, the third-highest cause of death in Mnazi Mmoja Referral Hospital and Bububu Military Hospital (the hospitals with the highest mortality rate on the islands) was pneumonia septicaemia (blood poisoning), which accounted for 7% of all deaths (MoHSW 2009: 45). This could point to shortcomings in hygiene and poor surgical management in these hospitals.
put recovering the costs before their patients’ welfare and showed little concern for their suffering. This is not an exceptional case and similar situations arise all over the country. For example, the death of a woman in the maternity ward made the headlines in Dar es Salaam in 2008, and in 2010 a newspaper report warned women of being talked into unnecessary caesareans by ‘selfish doctors’ who value personal gains over patients’ lives (Daily News 2010).

As a result of so many negative experiences with the public healthcare system, trust in biomedicine is not pervasive. In fact, many of my informants were afraid of visiting the hospital and were terrified of having to be admitted. ‘The only way you get out of the hospital is wrapped in a cloth [i.e. dead]’, I was often told, and people always took care not to touch anything when visiting a patient for fear of catching ‘bugs’ (wadudu). While the large majority are forced to cope with what they can afford, the small mobile elite turns to one of the better-equipped but expensive private clinics that have sprung up on the islands, pointing towards an increasingly ‘class-based’ differentiation of healthcare provision (Parkin 2006: 699).

The privatization of healthcare delivery has, in turn, led to the creation of a market for health in which practitioners of non-biomedical healing, too, have started to view their services as a marketable commodity, resulting in increased competition among a range of different healing practices and practitioners. Many of my informants claimed that the once-common herbalists, massage therapists, and spirit and Qur’anic healers who offer their services as a charitable act and pious deed have become very rare. Indeed, Zanzibar’s Traditional and Alternative Medicine Policy (2008: 6) calls for the regulation of local traditional healing and proposes developing ‘appropriate and profitable marketing, pricing and post-harvesting systems so that it can match with world market trends’.

The need for cash to access hospital-based and non-biomedical treatment has reached such an extent that deaths and severe complications caused by medical negligence due to the patient’s inability to pay have become common occurrences, and accounts of traditional healers detaining patients until they can pay their fees and threatening them with witchcraft attacks should they escape have posed a real concern for many of my research participants.

The treatment of AIDS (and the promise of a cure) has become a particularly lucrative business, fuelled by the rise of the AIDS industry that emerged out of globally concerted efforts to fight the pandemic. HIV-positive people in Zanzibar are very aware of the influence of economic considerations on their health and their dependence on donor support for the antiretroviral treatments that keep them alive. The stigmatizing nature of HIV/AIDS, the debilitating symptoms of the disease and the high costs of biomedical treatment make it an especially attractive market for treatments.

While my informants praised the introduction of free antiretroviral treatment in 2005, a cure (kupona kabisa) was what they were really hoping for. Consequently, many had already tried out one or several treatments that promised to eradicate the virus completely, and news about new, allegedly successful medicine against AIDS frequently arrived. People went home to their villages to find their own healers and bought medicines from all over the country, from places as far away as Kagera (where the Tanzanian epidemic started and people were thus assumed to have experience with its

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8 The incident is reported to have taken place in June 2008 in Mwananyamala Hospital in Dar es Salaam, which has been at the centre of scandals involving the intimidation of pregnant women to the extent that some mothers and/or their newborn babies have died during delivery. A probe team exonerated the hospital in the former case (Daily News 2009).
treatment), Dubai and Saudi Arabia. Herbal concoctions (dawa za miti shamba), the composition of which would come to the healer in a dream or with 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. Some of these cures were developed by long-standing healers, others traded by entrepreneurial self-pronounced healers, and some were even sold in backrooms by biomedical doctors who then observed their clinical effects on patients. While genuine attempts to relieve suffering undoubtedly are a motivation, healers also seem to be doing good business, to the extent that in 2004 advertisements that claimed to offer a cure for AIDS were made illegal. However, this did not stop constant demands for new therapies and treatments for opportunistic infections.

How do people cope with the high costs of severe and long-term illness in an increasingly monetized environment where most diagnostic and treatment routes require cash payments? Here the availability of a functioning social-support network becomes all the more important. Building up and maintaining extensive networks of support helps to spread everyday risks and uncertainties. However these networks often crumble under the stigmatizing and costly burden of HIV/AIDS.

Disintegrating networks of social support

There is common consensus among Zanzibaris that the extended family serves as the prime network of support. Nothing is considered as important as family relations, and a strong emphasis is placed on harmony within the family. Wealth does not necessarily need to be shared equally among family members, and in a community deeply involved in trade it is acknowledged that some people make more profit than others. In situations of need, however, it is compulsory to help. In addition to family obligations, neighbours (majirani) in Zanzibar also act as an important support system: living together creates relationships of responsibility, and community cohesion is generally strong. Neighbours play a central role in providing support for larger occasions such as weddings and funerals, and are supposed to recognize when a person needs help. Some of my informants reported that their neighbours occasionally gave them food or money when they were desperate, or gave their children a meal to relieve them of the stress of feeding their family. Work also creates relationships and feelings of responsibility. Colleagues support each other, and employers often help in case of sickness by contributing to the cost of medication and hospital visits, or they might even send the sick person on paid leave.

Together, the social network of family, neighbours, friends, colleagues and employers thus works as an insurance system in which moral debts are created for which a return can be claimed afterwards. But members of the social network do not only extend economic support; the emotional support they give by enquiring about a sick person’s health, by visiting and generally by showing that they care is often regarded as important as material aid. Nevertheless, long-term illness puts enormous

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9 Payments usually ranged from Tsh 150,000 to Tsh 500,000, which is a lot of money but not unaffordable. Many of my informants had mobilized their social networks to raise it.
10 Some long-standing community members (usually not recent immigrants) who do not have family even received constant support from their neighbours, as was the case of Mariam, an old widow with no children, who was fed and dressed on a daily basis by all the neighbours on her street.
strain on a social network and with rising costs it is often impossible to provide comprehensive and enduring care.

Moreover, situations occur in which disputes about family members’ liabilities arise, and support is denied or kept to an absolute minimum. These conflicts tend to take place in cases where the person in need is thought to have brought an emergency situation upon themselves through immoral behaviour, e.g. through drug or alcohol abuse, or through sexual promiscuity. All these behaviours are closely associated with HIV/AIDS, which is predominantly explained in Zanzibar as divine punishment. Local mosque communities do not play a major role in caring for the sick, and the moral interpretation of AIDS on the islands frequently leads to further ostracism from the community and exacerbates rather than helps the situation. Stigma, blame and financial costs come together and result in the disintegration of social support networks: it is plainly easier to justify high treatment expenses for a family member who is deemed an ‘innocent victim’. Recently, however, attempts in the Muslim community have been directed at redefining the ‘AIDS-as-punishment’ message into one of ‘AIDS-as-a-trial-from-God’, focusing on Muslim principles of compassion and caring for the sick rather than condemning or blaming them (Beckmann 2009). Ashura’s story offers insight into the self-sacrificing care that is extended by some family members, but tensions that arise even within the nuclear family demonstrate the fragility of the relationships of care that can easily break down from one day to the next leaving the patient to their own fate.

In 2005, Ashura, a 30-year-old mother of a small son, was terminally ill with AIDS. She had been hospitalized for four months with diarrhoea, severe nausea and serious dehydration. During this time, her mother had been with her: she slept at the hospital, went to work during the day, then home to wash Ashura’s clothes and prepare food for her, and came back to the hospital to care for her daughter. Three weeks after Ashura started to take antiretrovirals, a ZAPHA+ member took her to the hospital for a chest X-ray. Her mother had broken her foot and was hospitalized. Now Ashura did not have anybody to care for her, and there was no money for food. The family lived in a very basic makuti (coconut-palm leaves) thatched house in Kwahani in the Ng’ambo area of Zanzibar Town. They were having lunch when I visited some days later, a plate of plain rice with a small handful of spinach to share between everybody. Ashura’s mother was sitting on the floor with outstretched legs, unable to walk. ‘But we have a hospital appointment tomorrow, again,’ she said, biting her lip. ‘Last time Ashura just didn’t want to go, she couldn’t face making the journey down to the street to get a bus. But we had to pick up those drugs! So I had to get a taxi to come directly to the doorstep and pay the driver to take us to the hospital.’ Ashura’s sister, who also lived in the house, constantly scolded and blamed her for the infection and for bringing shame on the family. She had not made any effort to ensure that Ashura took her drugs while her mother was in hospital. She made it clear that she could barely tolerate her presence in the house and took care not to let her children get too close to their sick aunt. Weakened physically and mentally by the symptoms of AIDS, Ashura relied exclusively on her mother for her daily care, while the rest of her family network limited their care to ensuring she did not starve. Despite her antiretroviral treatment, Ashura died a year later in the summer of 2006.

Ashura’s story highlights the vital importance – and volatility – of a functioning social-support network for survival in Zanzibar. If this breaks down, the consequences are usually deteriorating health and death. While HIV rates are comparatively low on
the islands,11 AIDS is perceived as a major threat. A person who is often sick or shows any of the symptoms associated with AIDS attracts rumours, neighbours and friends stop visiting, and people in the street point fingers. ‘The worst thing about AIDS, the reason why we are so scared about it, is that if you have it, you won’t have any friends’, 29-year-old Hassan explained. The painful loss of part of or even one’s entire social network is not only emotionally scarring, it is also physically dangerous. In the absence of state-sponsored social-security services, a social network is vital for physical survival. Indeed in most cases I encountered in Zanzibar, the disclosure of one’s HIV status led to immediate abandonment or divorce, which hits women especially hard. Many HIV-positive women are left with several children and no, or only minimal, financial support. Many, therefore, hide their HIV status from their partner and family members. Once it becomes known that a person is HIV-positive, business often goes down: ‘who would want to buy anything from a *mwene UKIMWI* (a person with AIDS)?’ Zainab, an HIV-positive woman in her mid-forties explained. One member of ZAPHA+, Zanzibar’s only support group for those who are HIV-positive, reportedly died because nobody cared for her when she was sick and people threw stones at her and refused to sell her food. Such extreme cases of stigmatization occasionally occur in Zanzibar, but usually families provide at least a minimum level of care, supplying food and help with daily household tasks, such as washing clothes and cleaning the house. But many of my informants deplore a lack of kindness and compassion, and report that they are scolded by family members and treated with contempt. The family might attend to (*kuhudumia*) but not actually care for (*kujali*) the person. This points to the fact that caring for a sick person needs to be more than providing basic assistance – emotional support, expressed by showing empathy (*huruma*) and love (*upendo*), and a respectful way of interacting with the sick person (*kumheshimu*) are viewed as essential features of relationships with the surrounding social environment. Without these, several of my informants pointed out, life is not worth living, and suicide is sometimes considered.

Ashura’s story also demonstrates the financial costs of caring for a sick person, which go well beyond hospital bills and charges for drugs, and include expenses for food, water and transport. Ashura’s mother had never before taken a taxi, and the trip swallowed up a major part of the family’s income, but empathy and love for her daughter led her to decide against cost-effective considerations. Ashura’s sister considered it an unfair waste of precious resources on an undeserving, dying person. Such considerations about the efficient use of household resources are found in other parts of the region too. In northwestern Tanzania, for example, health staff often advised AIDS patients’ relatives not to waste any more money on medical treatment (Dilger 2010: 107). While free ARVs have been available to all eligible patients since 2005, the constant need to treat opportunistic infections could not be met by the majority of my informants. Antifungal creams, Septrin, Cotrimoxazole, painkillers, TB and STD medication, vitamins and good-quality food all place considerable pressure on family budgets. Although these drugs were officially free for PLHA at the government hospital, they were often not available, or were only given subject to bribes. Infections were left untreated, courses of treatment not finished12 or other forms of treatment were sought in an increasingly competitive market for health and well-being. So how do HIV-positive people cope with the loss or disintegration of social relations?

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11 Officially, Zanzibar has one of the lowest rates of HIV infection in Sub-Saharan Africa. According to the only published survey, HIV prevalence was 0.6% in 2002 (ZAC 2003: 1).
12 This results in ever-increasing drug resistance. Multi-drug-resistant strands of TB, for example, ravage the continent and cost uncounted numbers of lives every year (cf. Farmer 2001).
Purposeful relatedness: Entering the AIDS industry

An important part of coming to terms with the infection for most of my informants was the process of protecting their existing social network and building up new social relationships to replace those they had lost. One way of creating new support networks is to join a support group for HIV-positive people, such as ZAPHA+. As the only organization in Zanzibar that exclusively caters for and is run by HIV-positive people, it forms a self-governed self-help group for people living with HIV/AIDS. ZAPHA+ members provide mutual emotional comfort and reassurance, information about life with HIV/AIDS, and practical support through home-based care and help with household chores, food and drugs. New friendships develop and reciprocal responsibilities are established. Moreover, many joined in their search for a marriage partner, since rumour spread that this was the only place where HIV-positive people would find someone willing to marry them. Newly diagnosed single patients were often referred to ZAPHA+ by a concerned nurse for just this reason.

The extent to which these new social relationships can provide economic stability is relatively limited, however, since members largely come from the poorest sectors of society. But, importantly, membership of ZAPHA+ promises access to financial support through participation in the organization's income-generating activities, projects and events, and thus the AIDS industry, that rapidly growing economic sector that comprises doctors, donors, foreign experts, government officials, and those at the bottom, namely the sick.

The heavy involvement of donors in the field of HIV/AIDS (as, to a lesser extent, in other areas such as poverty reduction and women's empowerment), boosted by the design of the Millennium Development Goals and the establishment of several large funding instruments known as Global Health Initiatives in the twenty-first century, have led to the emergence of a global industry in which new career opportunities are arising. The value of this industry is enormous: global spending on HIV/AIDS totalled US$ 13.7 billion in 2008 (KFF 2009). Tanzanian government expenditure on HIV/AIDS for 2007/2008 was predicted to reach Tsh 568 billion, ‘a staggering one third’ of all aid flowing into the country and far beyond the ‘best case’ scenario of the 2007 National Multisectoral Strategic Framework’s financial assessment (TACAIDS 2007: 8). A small part of this funding is dedicated directly to supporting the activities of HIV-positive people.

However, members’ and donors’ views on the best way to support those who are HIV-positive have diverged. While members hoped that being poor and HIV-positive would entitle them to a share of the vast amount of money dedicated to HIV/AIDS that was reportedly entering the country, donors generally opposed the idea of funding basic needs. With the exception of acute emergency situations: money spent on saving lives is generally considered money well spent.
to make soaps, AIDS-awareness ribbons, clothes and knitted baskets. Some more entrepreneurial individuals sell food and drink in the queues at HIV clinics or products that cater specifically to this new target group, such as soaps and creams against skin rashes and barks and herbs against upset stomachs and headaches, which are common side effects of antiretroviral treatment. Overall, however, these income-generating projects were unsuccessful in providing a living for members who frequently complained that they did not get any or only very little payment for their work. They instead saw it as a pastime and their contribution to the organization. This has created conflicts with foreign volunteers who have invested their time to find opportunities for income generation because they felt that members were not pursuing their jobs seriously, and accused them of being lazy and opportunistic.

At a training course for peer educators facilitated and financed by Medicos del Mundo (MDM), for example, ZAPHA+ members complained that they did not get enough money for attending the course as the allowance was lower than usual (Tsh 3000 per day and no meals). The MDM representative replied that the training would give them the opportunity to get paid work afterwards without them having to disclose their HIV status. The argument escalated, with MDM accusing the ZAPHA+ members of being lazy and self-centred, and ZAPHA+ members in turn reproaching MDM unkindness and negligence towards the needs of sick people. ‘How can we concentrate all day if we don’t even get anything to eat? Your nutritionists teach us that we have to eat quality food, and then you make us sit here without lunch until the evening!’ a long-standing ZAPHA+ member angrily exclaimed.

While members who joined in search of substantial charity or business opportunities that would generate a viable income were mostly disappointed, they began to realize that their HIV-positive status could offer the opportunity of making a living from participating in the world of international development. Those who had been members of the organization for some time had certainly learned how to ‘navigate the AIDS industry’ (Boesten 2008). The importance of the role of people living with HIV/AIDS in the fight against the global pandemic, the perspective and the commitment they can bring to care and prevention was officially recognized in the promotion of the strategy for the Greater Involvement of People with AIDS (GIPA). This was formally adopted as a principle at the AIDS Summit in Paris in 1994, where 42 countries declared the Greater Involvement of People Living with HIV and AIDS to be critical to ethical and effective national responses to the epidemic (UNAIDS 2007). All major global players in the AIDS response have taken this on board. While the GIPA was criticized for being largely tokenistic and not providing any real opportunity for HIV-positive people to participate in decision-making processes, one result of the new strategy has been that ZAPHA+ members are now regularly invited to take part in stakeholder meetings, seminars and workshops on a whole range of subjects related to HIV/AIDS. These meetings grant a sitting allowance, usually upwards of Tsh 5000 per day to every participant, and a hot meal is often provided too. As many ZAPHA+ members have no income at all and rely on support from family, friends, and neighbours, this has proved a real incentive for them to take part in meetings.

Project funds have additionally been sought from a wide range of national and international aid agencies and ZAPHA+ has been able to secure large amounts of funding from leading international organizations (e.g. the Steven Lewis Fund, the Clinton Foundation, USAID). ZAPHA+ has in fact served as a locomotive for other local HIV programmes, and donors – in line with GIPA principles – have been eager to fund
projects that involved people living with HIV/AIDS, unlike local organizations.14 This
donor demand for HIV-positive people has turned their sick bodies into a potentially
valuable resource, and members have quickly learned to adjust to the logic of
international development, which requires an amount of suffering to justify
intervention. They have become skilled at ‘telling a good story’ and whenever potential
donors show up, one of the members ‘presents her story’ (kutoa hadithi), realizing that
the more heart-breaking it is the better the chance of getting through to the donor. ‘You
have to make them cry,’ Rahma was advised when preparing her speech for World AIDS
Day, ‘and don’t forget to ask for what we want: more support, more respect, and
treatment’. This ability to tell a good story, Nguyen (2005: 133) points out in his
analysis of a local grassroots organization in Burkina Faso has become key to survival
and the narratives of distress are used tactically, especially in contexts characterized by
limited resources. Ironically, AIDS, the very thing that resulted in them losing their
economic basis, has now become a major source of income for those who have managed
to turn their HIV-positive status into a marketable commodity.

ZAPHA+ members also understand the kinds of suffering that are particularly
likely to attract funding: mothers and children, and orphans who were abandoned by
their families. Projects aimed at supporting these vulnerable sectors of the population
are likely to receive support, as are projects geared at self-sufficiency, such as micro-
loans and small-business development. The importance of juggling the catch phrases of
the development industry has been recognized: all ZAPHA+ proposals boast
development terminology and acronyms such as ‘home-based care’ (HBC), ‘income-
generating activities’ (IGA) and ‘poverty alleviation’, ‘capacity building’, ‘peer education’
and ‘peer counselling’, to name but a few. Moreover, people have learned to fashion
these projects to their own needs and circumvent donor agencies’ conditions, a practice
that has been observed in other parts of Sub-Saharan Africa too.15 Instead of merely
asking for food support, for example, ZAPHA+ applied for (and received) US$ 25,000 for
a one-year nutrition project, where a ‘nutrition committee’ consisting of ZAPHA+ members
prepared a meal for all members twice a week, using locally available, reasonabably priced but nutritious ingredients. The recipes were to be collated in a
cookbook for HIV-positive people in resource-limited settings. It is these kinds of
projects – that can be applied to other geographical settings and are not predominantly
directed at ‘feeding’ people – that, not surprisingly, are enthusiastically received by
donors, although for the majority of members the important part of the project was
being fed a hot meal twice a week. The large amounts of money flowing into the country
for AIDS thus make acutely visible the areas that are not supported, such as pervasive
food insecurity, unveiling neoliberal agendas of state reform which shift responsibility
for basic services to the population. The fact that so much money seems to be available

14 There were over twenty local non-governmental organizations and several governmental institutions working
specifically on HIV/AIDS in Zanzibar, but many have neither visited nor collaborated with ZAPHA+ in any
way. While all local HIV/AIDS NGOs were part of ZANGOC, a Zanzibari umbrella organization, there were
few connections between them. For example, there is no formal referral system between the Zanzibari
organization for AIDS orphans and ZAPHA+ (arguably a major ‘producer’ of AIDS orphans), and many
ZAPHA+ members did not know that support was available for orphans. A striking example of the reluctance to
work with ZAPHA+ was Zanzibar’s First Lady and ZAPHA+’s patron, who organized a concert to raise money
for HIV/AIDS but did not even inform ZAPHA+ about it. Several ZAPHA+ members have suggested that
prejudice and the fear of contact with HIV-positive people are the reasons for the widespread unwillingness to
let them participate, claiming that even Ministry of Health officials (who should know about HIV transmission)
were afraid of shaking their hands.

15 For a compelling account of a youth group in Burkina Faso, see Nguyen (2005).
has given rise to heavy competition and damaging rumours: about the West already knowing of a cure for AIDS but withholding it from Africans for economic, political or racist reasons, or about HIV-positive people who are allegedly getting rich from these funds.

Indeed, many ZAPHAs members are trying to live off the various training courses, meetings and workshops run by external agencies that supply an irregular but considerable income from which beneficiaries can live quite comfortably. The AIDS industry can thus offer new opportunities to the impoverished and marginalized. These include financial opportunities but also the potential to establish new identities and social status through acquiring leadership positions and gaining respect within ZAPHA+ and among stakeholders. Activism as part of ZAPHA+ means creating and maintaining links with national and international organizations, gaining access to governmental meetings and engaging with local, regional and national government authorities – in short, establishing links with and gaining insights into institutions and processes that previously were entirely beyond the reach of most members. Participation in PLHA groups can thus be empowering and an opportunity to take agency: a form of self-marketing that can lead to self-reflection and self-construction as a ‘person living with HIV/AIDS’, and to ‘producing and feeling’ their identity as PLHA, similar to the processes of ‘ethno-preneuralism’ – the commodification of ethnicity and indigenous identity described by Comaroff & Comaroff (2009). Financially, participation in the AIDS industry can, for a few, lead to personal relationships with a wealthy Westerner who may provide substantial on-going support. This is the lottery ticket that many hope for, and a major incentive for investing time in participating in activities that do not always carry meaning or produce immediate benefits.

However, this is not a certain game. Some individuals manage to carve out a living by giving testimonies, participating in workshops and seminars, and working as home-based carers, peer counsellors or income-generator. But with growing numbers of members, many will never get the opportunity to enter the ranks of the AIDS industry. At the same time, these opportunities come at a cost as the disclosure of one’s HIV status can pose risks, as the following case studies demonstrate.

Markets for sickness: The commodification of misery

On 1 December 2004 I joined some ZAPHA+ members at the Amani Stadium in Zanzibar, where the annual World AIDS Day was celebrated. These celebrations culminated in the presentation of prizes by Zanzibar’s President Amani Karume to organizations that had carried out outstanding work over the past year. While ZAPHA+ members felt honoured to receive a prize, it was difficult to find volunteers willing to accept the certificate in public. Only a handful of people on the islands were openly HIV-positive, mainly among ZAPHA+’s leadership. Most ordinary members preferred to keep their HIV-status secret. Two members finally decided to ‘go public’ to show that they were not ashamed of being infected. One was Rahma, a 43-year-old single mother of four children. She had tested HIV-positive in 2000, having cared for her sister who suffered from AIDS for over a year. After her sister’s death, she took in two of her sister’s orphaned children and supported the remaining three. The other woman was Amina, a 30-year-old mother of one son. Both were divorced, had been members of ZAPHA+ for several years, and were outspoken and self-confident. Amina’s family, and Rahma’s employer and colleagues at the hospital, where she worked as a cleaner, knew
of their HIV status and had been supportive. However, when Amina proudly accepted the certificate from the President, and when Rahma gave a passionate speech advocating the rights of HIV-positive people, the local TV station TVZ transmitted their public acts into the households of the Zanzibari people. The next day, Rahma was dismissed from her job and Amina was chased away by her family.

Both recounted how their families, friends and colleagues had not blamed them for their condition, but that the public disclosure of their HIV status was unacceptable to them. To have AIDS is aibu (shameful) and to admit it openly meant they had disqualified themselves from participation in the social world of ‘normal’, i.e. non-infected, people. As part of a social network, Rahma and Amina had disregarded the needs and feelings of their networks’ other members. Disclosing their HIV/AIDS status in the workplace could scare off clients, especially in a hospital setting due to fears surrounding the infectiousness of the virus, and the family of an HIV-positive person is subject to stigmatization in the wider social environment too. Since AIDS is so closely associated with moral failure, HIV infection is seen to reflect on the person’s upbringing and thus on his/her family. Implying that moral and specifically sexual norms must have been broken, it indicates a clear disregard of the rules of respect and obedience to one’s parents and elders. A family who has a member who is known to be HIV-positive will become the centre of attention and gossip, and the family members’ general tabia (character, behaviour) will be re-evaluated. Consequently, it may be more difficult to find appropriate marriage partners even for non-infected family members. A person’s public disclosure of their HIV status thus has implications beyond the individual sufferer and affects the larger social network of which s/he is a part.

Openness and testimony, emphasized in the global discourse on AIDS as an important means of fighting stigma and coping with one’s infection, for individuals like Amina and Rahma thus carry the danger of destroying what is left of their social support network, and harming those closest to them. Not many are willing to take such risks. To still benefit from the AIDS industry, members have devised strategies to minimize the dangers disclosure entails. Just as in their private lives, they disclosed their status step-by-step, carefully testing the waters and weighing up the risks before they trusted a person with such powerful and dangerous information. Many chose to engage in lower levels of disclosure, guarding the spaces in which they speak about living with the virus: they avoid public and broadcast events, but attend closed donor meetings and workshops where the possibility of running into a relative or neighbour is low. Others justified their presence at ZAPHA+ by claiming to do HIV charity work. Ahmed, a carpenter in his mid-thirties, for example, collected training and workshop certificates he had gained through his work within ZAPHA+ so that he could show them to his employer and colleagues should they ever wonder why he spent time with HIV-positive people. In fact, when the organization received a new door sign that suggested the group’s association with HIV/AIDS, many members refused to come in for fear of stigmatization, and women started to wear face veils when entering, although the sign did not even mention that the organization was only for HIV-positive people.16 These members’ strategies about hiding their infection contradict the discourses on the value of openness and empowerment that form part of the donor script and that are promoted within ZAPHA+, despite the fact that many genuinely want to make a change.

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16 It reads: ‘ZAPHA+. Place of friendly services for young people, on reproductive health, AIDS, teenage pregnancy and drugs’.
Knowledge of and openness about one's HIV status, HIV policy planners assume, will reduce the stigma over time. 'Pima ufaidhike' ('test for your own benefit') is what a T-shirt by the Tanzanian Commission for AIDS (TACAIDS) declares. Many however cannot afford to carry the burden of stigma and complain that donors do not really care about their daily struggles: ‘What benefit do I get exactly?’ Zaina, a poor, older member, asked bitterly. Maria, a former member of the Kigoma branch of Service, Health and Development of People Living Positively with HIV/AIDS (SHEDEPHA) received a place on an HIV-awareness seminar, and thus a daily allowance. In return, she was asked to tell her story and disclose her HIV status in a large hall in front of an audience of Kigoma citizens. ‘I did it, I said openly in front of all these people that I was HIV-positive, and what do you think I got? Only Tsh 5000. I took this risk while other PLHA leaders just sat there and said nothing and got all this money.’ After this experience she told them she did not want to be a part of their group any longer. Although Maria subscribes to global scripts of openness and de-stigmatization, she was explicit about feeling exploited by donors’ consumption of PLHA stories in the drive for increasing openness about HIV/AIDS, and the fact that they rarely ask what happens to people after disclosure. The lack of support mechanisms that buffer the impact of disclosing in a largely hostile environment, in combination with the extreme poverty of many PLHA who are responding to the demands of a powerful industry that promises both life-saving medication and financial benefits, makes the commodification of sickness and misery highly transgressive, and the sick body a ‘commodity of last resort’ (Scheper-Hughes 2002: 2).

Their public acts resulted in Amina and Rahma losing central parts of their support networks, leaving Rahma to feed her children without an income, and Amina without a caring family or a place to live. Rahma started offering laundry services to get by, which is physically arduous and badly paid. She claimed she earned Tsh 10,000 to Tsh 12,000 per month from this job, not nearly enough to sustain a family. ‘If I really stretch it,’ she said, ‘I need Tsh 25,000 per month to feed them all. I can’t even think of the last time I ate meat; it must be at least three months ago. One kilo of meat is Tsh 2,000, you know, and a small piece of fish is Tsh 800. And to prepare fish you need tomatoes, onions, potatoes... I use dagaa (small dried fish), and in the morning I eat a cup of uji (porridge). Sometimes I boil water without tea leaves because I can’t afford any.’ She now relies on her income from the AIDS industry, micro-loans and income-generating projects, participation in meetings and education sessions and money from weekly Saturday ‘therapy’ meetings. This way she can accumulate Tsh 30,000 per month, but this sort of income is irregular. If there is no work within ZAPHA+ she makes soaps and sells them in the neighbourhood. Smiling proudly, she tells me that her neighbours say she takes care of her children better than most men. The neighbours also help out from time to time. ‘I pray to God,’ Rahma says, ‘I ask Him to help me with the children and to find us something to eat. And sometimes I’m walking home and a neighbour says: “come on in!” and gives me beans, rice or Tsh 500. There were so many things I wanted to do, so many plans I had made. But now it is difficult because of the virus. Now I only want to live until my children are grown up.’ Rahma has to deal with enormous stress. Her nineteen-year-old son is living with his friends: he left their home of his own accord in order to help her. One of her deceased sister’s children is being abused and beaten by her aunt. ‘When she ran away and begged me to let her stay here with me I said: “Endure (stahimili)! I don’t have any space for you at home”. But both children are supported by me. If I could afford it, I would want them all with me at home.’ In such circumstances, public disclosure of her HIV status may be seen as a
desperate attempt both to gain access to financial support and to redefine a highly stigmatized identity by emphasizing altruistic motives and moral responsibilities to care and protect. Its potential for empowerment and agency through self-marketing is limited by the constraints of the market, where capacity for sickness stories is limited in the face of increasing competition, and where financial value placed on narratives of suffering is too low to provide a sustainable livelihood for most PLHA.

At the same time, self-marketing as an AIDS sufferer and an ARV-supported survivor can contribute to crumbling social relationships by evoking the appearance of making money from their stigmatized condition. Amina managed to carve out a career for herself within ZAPHA+: she was elected the group’s secretary, which provided a small monthly salary. More importantly, as secretary, a number of invitations from development organizations to participate or speak at meetings and seminars were addressed directly to her, and thus opened up opportunities for further income. Allowances paid for participating in such meetings usually range from Tsh 5000 to Tsh 10,000 a day, and up to US$ 50 per day if the workshop is held outside Zanzibar. These are considerable amounts of income compared to the average salary on the islands. However, spaces were limited and competition was high – ZAPHA+’s membership had grown to several hundred by the summer of 2007, due to an efficient referral system of newly tested HIV-positive people by ZAPHA+ members working as peer counsellors at HIV-testing sites in Zanzibar.

While for some members, like Amina, ZAPHA+ had replaced social networks that had disintegrated under the burden of the stigma of HIV, the newly built relationships were subject to conflict and tension too, many of which arise from the competition for scarce resources. The fact that money seemed to flow to ZAPHA+ in amounts almost incomprehensible to many members, who come from the poorest sectors of society, was a major incentive for joining the group, which managed to secure several large grants worth thousands of US dollars. Apart from initial attendance expenses of Tsh 3500 per person for the weekly ‘therapy’ meetings (which soon declined when membership rose), most members saw very little of this money, which was invested in running an office, providing home-based care for sick members and income-generating activities. The fact that funds were too scarce – and not intended – to care for every member’s needs was a constant source of tension and led to conflicts within the group. Difficult decisions had to be made: ZAPHA+’s leadership had to negotiate the demands of stakeholders who requested PLHA participation by qualified individuals who would follow and engage in discussions at meetings or reliably present their testimonials, with their members’ demands. Spaces for attendance at meetings or workshops had traditionally been allocated by voting at the Saturday meetings. Spaces were assigned on the basis of need and level of involvement: active members and those who were in acute financial difficulties were usually particularly favoured so that they could benefit from the daily allowance and the food provided. As a result, members with no English skills or technical knowledge sat in important policy-planning and donor meetings and

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17 Mean per capita annual income in Zanzibar was Tsh 198,907 in 2004/5 (Zanzibar Household Budget Survey 2004/5: 108).
18 There are other sources of tension too, including romantic and sexual affairs among members and resulting jealousy, and cases of abuse of power for sexual favours and privileges.
19 These meetings were intended as group therapy meetings, but organizational matters, upcoming events or projects were discussed, or the sessions were used to run education sessions on HIV/AIDS-related topics.
could neither represent ZAPHA+’s interests nor report back to their members. The following example illuminates the difficult negotiations between ZAPHA+ and their stakeholder network.

Khadija had been pushing for a workshop place for months. She and other ‘ordinary’ members were angry at the leadership who she claimed used their privileged position as gatekeepers to limit opportunities for members to gain access to workshop spaces. Khadija was a long-term member of ZAPHA+ but had never been able to connect well with the other members. As a barmaid selling sex and alcohol and drinking regularly, she had been marginalized within the group, despite the organization’s strong commitment not to stigmatize anybody. After she and various other members had caused some stir in a meeting with ZAPHA+’s main funder by openly accusing the leadership of siphoning off money, she was finally selected to tell her story at a teachers’ workshop organized by the Peace Corps. When they came back in the afternoon, Tausi, an experienced public speaker who had accompanied her, was fuming: ‘Khadija pulled out! First she made such a fuss and kept hassling us about getting a place at a workshop, and then she doesn’t do her job! Charles [the Peace Corps trainer who recruited ZAPHA+ members for his workshops] was also angry and said he’d never work with ZAPHA+ again!’

Khadija’s story demonstrates how ZAPHA+ members were very aware of their dependence on donors and the need to play by their rules, which include reliability in providing the services demanded, accountability and transparency in implementing projects, and demonstrating eagerness to provide voluntary or low-paid services in the ‘fight against AIDS’, to be fought in unity as HIV-positive people, side by side with the organizations that supported them. Some members had embraced the struggle to contain the epidemic and protect others from infection. For many, however, participation in the AIDS industry came out of the desperate quest for survival when there was no one else to turn to anymore. Yet donor dependency, the insufficient availability of funds and the diverging views of members and donors on appropriate ways to invest these funds have been a major hurdle to building the unity that is considered so important to make headway in the fight against AIDS. It instils tension and conflict among members, and thus directly opposes their efforts to build new social relationships that can be trusted in times of need. The uneven dispersal of funding generates mistrust, which can erupt in open conflict and threats, as in the case of Amina.

Amina had been at the ZAPHA+ office almost every day for years, and had worked hard to gain members’ respect. In her position as secretary, accusations grew louder, however, about how she misused her position by taking up the invitations to send a ZAPHA+ member to meetings herself without giving members the chance to choose a suitable representative. When Amina died of AIDS in the summer of 2008, very few attended her funeral. I was struck by the division among formerly close ZAPHA+ members at the funeral: they formed two groups and sat on different mats, some feet apart. Some were crying but there were also whispers: that Amina had brought her demise upon herself; that she did not deserve better. Her friend later recounted: ‘Some members are glad that she died, they were happy! They said she had taken money and didn’t pass on letters [invitations], so that she always got to go to seminars. Some even wore kanga that read: Umeuliza umepata (‘you got what you asked for!’).’ As assistant secretary, she became ZAPHA+’s new secretary, usually a highly desirable and

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20 The fact that high-level meetings were usually held in English, without translators, and that a level of technical knowledge beyond most members’ ability was required for full participation demonstrates the lack of commitment among donors to involving PLHA in decision-making processes in a meaningful way.
prestigious position, but she only took the job reluctantly: ‘I’m scared of being secretary. They said I should quit my other job and work for ZAPHA+ fulltime, but I won’t do it. I’ll get a fly stuck in my nose (nitapewa nzi puani) for nothing.’

These conflicts have reached beyond ZAPHA+’s members and have included the wider society. The vast amounts of money circulating in the newly emerged industry around AIDS have led to accusations that ZAPHA+ members only pretend to be HIV-positive in order to make money. These accusations reflect the perceived injustice of investing so heavily in people who are largely thought to have brought their own suffering upon themselves, while neglecting the needs of the ‘innocent’ people who are also suffering from poverty and illness. Moreover, with antiretroviral treatment available on the islands now, HIV has become more invisible, and many PLHA look as healthy as everyone else. ZAPHA+ members must therefore constantly take care that they reconcile conflicting sick roles, as Zanzibari society defines an AIDS sufferer by physical symptoms and mistrusts claims to HIV-positive status by healthy-looking individuals. The donors’ desired ‘sick role’ is tending to be that of the empowered survivor, healthy through antiretroviral treatment, and transformed in attitudes and behaviour through their interventions. The accusations show how the AIDS industry could damage the fragile position of PLHAs even more, adding another layer to HIV-related stigma by inserting an economic component in the already existing fear and hatred. They also demonstrate the extent to which monetization has become a focal point of referral, and how the fierce competition for scarce resources in an increasingly monetized environment serves to instil jealousy and suspicion and threatens to damage carefully rebuilt social relationships.

**Conclusion**

The rise of markets for health in the wake of neoliberal moves towards the privatization of healthcare has shifted the problems concerning health services in Zanzibar from availability to accessibility, and increasing the need for hard cash has limited poor people’s access to healthcare and treatment options. This trend captures biomedical and non-biomedical sectors of healthcare alike. I argue that related to these trends towards marketization, privatization and individual responsibility is a decline in affect and emotion in the provision of care. The newly emerged AIDS industry shows these trends very clearly, opening up opportunities to make profits on a previously unknown scale. In this industry, the very state of ‘being sick’ can become a commodity, a source of income. Consequently, not only have healing practices and substances become commodified, the diseased body and its stories of suffering can also be turned into a commodity, something that can be marketed and serve as a potentially major source of income.

However while the AIDS industry has opened up new opportunities for the impoverished and marginalized, most do not enter into it lightly as they are fully aware of the dangers involved in the disclosure of their infection. Just like the commodified organs Schepers-Hughes (2002: 2) describes in her analysis of organ trafficking, which become ‘an object of desire for one population and a commodity of last resort for “the other” and socially disadvantaged population’, HIV-positive people in Zanzibar (and other poor and marginalized countries) are using their bodies, their stories of suffering

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21 This alludes to her fears of being targeted by witchcraft attacks out of jealousy.
and recovery, and their HIV-positive status as a last resort. The fact that they risk so much by taking this step is evident from the small number of people who dare to do so: only a handful of people in Zanzibar are open about being HIV-positive and are willing to speak in front of others about their infection. As long as openness and disclosure of one’s HIV status result in the destruction of a person’s social relationships and means of survival, and in the absence of real participation in decision-making and planning processes, it is difficult to see how PLHA participation in the AIDS industry can lead to their empowerment, as envisaged by many organizations working in the field. Under these circumstances, their gains rarely move beyond the short-term financial benefits offered in return for their testimony, and HIV-positive people become collaborators in their own exploitation, consenting to being reduced to a ‘most miserable commodity’ (Ibid.: 8).

Ironically, it is the more philanthropic, human-rights-based approach to HIV/AIDS intervention that places HIV-positive people as actors in this industry, calling for interventions to be based on principles of positive living, empowerment and partnership. Yet the donors’ preference for saving lives, while neglecting the livelihoods and social persona of the saved, exemplifies the reduction of life to ‘bare life’ (Agamben 1998). This is becoming more and more apparent in neoliberal regimes of care. Anthropology has an important role to play in unveiling these processes that are found in the multiple layers of meaning produced at the intersection of local and global discourses and practices around the control of large-scale health threats. Analyzing strategies for the fight against AIDS through the lens of processes of commodification highlights the potentially transgressive nature of (undoubtedly well-meaning) approaches to de-stigmatization and empowerment and points to the contradictory forces at play in the realm of global health interventions.

References


