



# **Precarious Future: Community Volunteers and HIV/AIDS in a Tanzanian Roadside Town**

**Dr Jelke Boesten**

**ICPS WORKING PAPER 4**

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# **Precarious Future: Community volunteers and HIV/AIDS in a Tanzanian roadside town**

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## **Abstract**

This study focuses on a widely promoted belief that community-driven and community-based interventions for development are not only cost-effective, but also just and democratic. In particular, this study examines community-based initiatives with regard to HIV/AIDS in one Tanzanian roadside town. The interventions I discuss suggest that increased community participation does not automatically lead to more equitable access to services, to the empowerment of the poor, or even to the planned service delivery at all. Dependence on local volunteers with multiple motives and interests can hamper the relationship between provider and beneficiary. A concern for minimal state involvement and maximum decentralisation can easily lead to institutional abandonment, and trust in an undefined 'community' can prevent rather than encourage coordination at community-level. As I discuss below, such factors can result not only in a service not being delivered, but can also readily lead to increased local conflict over scarce resources, increasing unfulfilled expectations, affirmation of inequalities, and government neglect. In the absence of a strong institutional framework such as the state, community structures and social relationships – unquantifiable and often particular to specific locations – seem central to the functioning of community-based development interventions, including those of AIDS related prevention and care.

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## **Precarious Future: Community volunteers and HIV/AIDS in a Tanzanian roadside town.<sup>1</sup>**

**Jelke Boesten  
(University of Bradford)**

In March 2005, Mrs Majogo, a community volunteer working for people affected by HIV/AIDS in her town, took me to meet one of her clients, Elisa. Elisa, a 30-year old, HIV-positive mother of three, transmitted the virus to her last-born when she gave birth in her home. She and her baby were both tested positive after the birth. The baby is often sick, as is Elisa herself. Elisa's mother is also HIV-positive, while her father and sister died of AIDS some years previously. When she feels well enough, Elisa earns some money selling food along the road where truckers stop to eat and relax. The Church to which she belongs helps her sometimes to buy medicines, and the local physician treats her baby free of charge, as she does not have the money to pay him. Elisa is a member of the local self-help group of people living with HIV/AIDS, and Mrs Majogo and her community organisation also help out: they distribute World Food Programme food baskets for families affected by HIV/AIDS, and, as Mrs Majogo stresses, Elisa receives half a yearly portion. A day after the visit that Mrs Majogo and I made, Elisa sees me walking past her shack and calls me in. In contrast to the polite conversation we had the day before, Elisa now wants to tell me the inside-outs, gesturing angrily, about Mrs Majogo and her 'business'. In her absence, Elisa accuses Mrs Majogo of stealing from the World Food Programme food baskets and of threatening and intimidating her and her fellow-beneficiaries. She even insinuates that Mrs Majogo translated Elisa's words wrongly to me just to give me a good impression. Elisa insists that she does not receive the claimed half-portion, but only a quarter. Later that afternoon, Mrs Majogo calls me in as she has heard I talked to Elisa behind her back: although I tell her nothing about our conversation and the accusations made, Mrs Majogo insists that I cannot trust 'these' people.

Elisa's story shows us that while she is very poor and feels abandoned, in fact she is supported by a wide range of community actors, including the Church, community organisations, benevolent individuals such as the doctor, and her own kinship network. Nevertheless, her situation is one of survival, and does not seem to improve at any rate. In addition, Elisa's story suggested the presence of rising conflict over donated resources, institutional affiliations, and community power structures. Mainly, the encounter with Mrs Majogo and Elisa raised a set of questions that are often overlooked in studies that investigate community initiatives against HIV/AIDS since they are not quantifiable. Based on ethnographic fieldwork in the Tanzanian roadside town that is home to Elisa and Mrs Majogo, I address the following questions in this paper: a) how does the

relationship between institutions (such as World Food Programme, WFP from now on), community-based workers (such as Mrs Majogo) and beneficiaries (such as Elisa) positively or negatively influence the delivery of basic services to HIV- affected populations at community level? and b) how do the personal interests of community-based workers influence their performance?

The paper focuses on three community-based initiatives against HIV/AIDS in one Tanzanian town. The study links up to a growing interest in examining community-driven development initiatives, understood as interventions that support the empowerment of the poor by increasing local participation in development and giving communities control over subproject resources and decisions (Kumar 2005: ix). Forming part of a wider comparative research project, this study aims to go beyond statistical indicators to examine less tangible factors that might influence the functioning of community-driven development (Boesten, Cleaver, and Toner 2006). The interventions I discuss suggest that increased community participation does not automatically lead to more equitable access to services, to the empowerment of the poor, or even, to the planned service delivery at all (see also: Chambers cited in Kumar 2005 pp. 151-153). Dependence on volunteers with multiple motives and interests can hamper the relationship between provider and beneficiary. A concern for 'cost-effectiveness'<sup>ii</sup> can easily lead to institutional abandonment, and trust in an undefined 'community' can prevent rather than encourage coordination at community-level. As I discuss below, these factors can result not only in a service not being delivered, but can also readily lead to increased local conflict over scarce resources, increasing unfulfilled expectations, affirmation of inequalities, and government neglect. However, the case studies also suggest that communities and community organisations are resilient and creative, and that we need to look at perhaps less obvious possibilities provided by community-based projects.

This research is based on predominantly ethnographic material gathered over a period of twelve months. In addition to four fieldwork trips each averaging three weeks, I liaised closely with two Tanzanian research assistants who lived permanently in the area. Working with such a team improved continuity, trust with participants in the research, and the possibility of following up on developments. Open and semi-structured interviews, group discussions, informal interviews, and conversations were carried out with community leaders, people living with HIV/AIDS, their family members, health care personnel and community-based workers (CBWs). In addition, participant observation, including following-up on the many rumours about people and organisations such as the above tensions between Elisa and Mrs Majogo, and diary writing and photo-diaries made by people living with HIV/AIDS were important. Minute books and other relevant documentation were also studied. This method of examining community-driven service delivery does not provide for quantitative data regarding improvements made in particular sites. However, it does provide qualitative information about mechanisms of inclusion and exclusion, about informal and formal institutions,

and about attitudes and behaviours that could enhance or obstruct particular interventions.<sup>iii</sup> First, I outline the development of discourse and practice with regard to community-driven development and HIV/AIDS, then I present the case study and the three community interventions directed at HIV/AIDS, after which I close specifying the observed issues with regard to community-based HIV/AIDS interventions.

### **Community interventions, health care, and HIV/AIDS**

The idea that the community is ‘the appropriate vehicle and target of change’ (Creed and Brooks 2006) and the basis of the solution to challenges in development has led to widespread adoption of community-based intervention methods by both NGOs and the state. Major international funding agencies encourage such an approach and NGOs increasingly seek community-based partners in development. States, in turn, are expected to seek a balance between central governance and decentralised participation and implementation. Underneath this rhetoric of increased participation and community ownership, a neo-liberal logic of decentralisation and privatisation dominates service delivery schemes. Within the discourse, such a strategy is assumed to be a cost-effective *and* democratic way of delivering services. However, in the case of HIV prevention and care the result seems to be that the task of caring for the already sick, a palliative task when no medicines are available, is passed on to voluntary, often insufficiently trained and compensated, community members (Farmer 1999). National and international NGOs are slowly filling some of the gap between inadequate private and public service delivery systems. When taking a closer look at the actual situation in towns and villages, one sees that communities struggle to survive in an ambiguous, and often unclear, institutional space.

In Tanzania, the government centralised coordination of AIDS policy in one institution, the Tanzania Commission for AIDS, TACAIDS, in 2001. At the same time, NGOs set up their own coordinating body as TACAIDS was struggling to allocate money. TACAIDS did develop a comprehensive National Multisectoral Framework for 2003-2007, and set up a decentralised system of funding, coordination, and implementation. Community-based responses are central to this framework, for which a decentralised institutional support system is set up. Officially, a system of regional and district expert committees feed into existing community initiatives and support newly set up village health committees and community-based workers (Mfangavo 2005). Unofficially – based on media reports, and testimonies of community and district leaders – funds get stuck somewhere on the way, capacity-building does not always have an expected trickle down effect, and the necessary political will is often absent. The policy is implemented in a fragmented and patchy way. Nevertheless, the Framework is there and receives the support of many regional and district councils that are eager to organise prevention measures and to support and set up initiatives to provide care for the chronically ill beyond the scarce hospital facilities. Although communities have multiple problems with organising their own service delivery in

an area so saturated with ambiguous meaning as HIV/AIDS, their commitment is paramount precisely because a centralised, state-led response is unlikely to be functioning any time soon. Despite (international) investment in hospital-based treatment in Tanzania, the vast rural areas will hardly benefit from such advances and are in dire need of community-based care systems. Thus, while the community-based approach to health care and HIV/AIDS is beset by multiple problems, it also seems the only short-to-medium term solution to urgent needs among the Tanzanian population.

Although community-based development is currently in vogue among development partners, this approach is not new. The mobilisation of community-based, mainly volunteering, health care workers has been central to national and international efforts to expand primary health care services to underserved and remote areas since the late 1970s and early 1980s (Berman et. al. 1987; Swider 2002, Boesten 2005). Today, similar health care initiatives are being set up as part of a variety of community-based efforts to provide care for HIV-positive people and improve prevention strategies (Uys 2002). Institutions such as World Health Organization, the World Bank, and international NGOs train and support community volunteers in the hope that they can provide home-based care, family planning, dietary and hygiene advice, and administer daily medicines. Community-based approaches to health care need to improve access to care in remote areas and for poor people. In the case of HIV/AIDS, such increased community participation is supposed to improve prevention and provide support to family-based carers in poverty-stricken areas. Deploying community-members to provide a link between health care professionals and home-bound patients and their carers could relieve a burden on both and improve the care provided. Again, while these ideals of self-help in a neo-liberal age are sustainable on paper, they rarely prove to be so in practice. Lack of actual institutional and infrastructural support seriously hampers the success of community service delivery systems (Boesten, Cleaver and Toner 2006). However, 'home-based care' systems are underpinned by still another set of assumptions, however, which are strongly related to the social context of the disease.

Home-based care programmes for HIV/AIDS patients that rely on volunteers were first set up in Europe and the United States to reduce the financial costs of hospital-based care and to relieve the physical and emotional pressure put on more traditional carers such as family members. In particular, home-based care was meant to give patients the psycho-social support that was greatly needed. In Africa, home-based care programmes were set up in several countries in the late 1980s in order to increase access to care in a context of substandard healthcare conditions and an increased health burden caused by AIDS. In some cases, NGOs and/or government agencies trained community-workers to help family members in the delivery of home-based care (Uys 2002). However, in most African settings, there is a lack of medicines, lack of formal public support for the majority of poverty stricken victims, and an unstable and/or unconstructive

institutional environment. In such circumstances, the meaning and content of home-based care is often unclear.

In addition to resources, home-based care programmes need a sense of community, forms of solidarity that encourage volunteers to provide support to people living with HIV/AIDS (Ogden and Nyblade 2005).<sup>iv</sup> Whereas community participation is common, and volunteering in community tasks is part of the organisation of Tanzanian villages, in the case of HIV/AIDS the nature of community solidarity needs more than willingness to perform tasks for the good of the collective. Such solidarity is not self-evident in a world where HIV is strongly associated with sexual promiscuity and being HIV-positive is often associated with prostitution – among other ‘evils’ – in a heterosexual and very unequal context.<sup>v</sup> As a result, HIV-related stigma often results in violence and ostracism, in ‘social death’ (Robins 2005). The stigma and social exclusion associated with HIV makes socio-psychological support for people living with HIV/AIDS even more important, but simultaneously more difficult as (the absence of) solidarity is the fundamental problem. Such solidarity, necessary for the establishment of an effective home-based care programme based on the labour of volunteers, is not necessarily present in the targeted impoverished political or geographical communities. However, as we will see below, networks of people living with HIV/AIDS that call themselves ‘communities of hope’, are creating forms of identification and solidarity based on their health status, which might provide for the necessary commitment for effective home-based care (Manchester 2004, Robins 2005).

Home-based care includes three basic tasks: administering medicines in the home in order to reduce hospital visits, personal care such as helping with washing and dietary advice, and psychosocial support, including providing support in carrying out domestic tasks (Thomas 2006, Chimwaza and Watkins 2004). The last two tasks are in support of more traditional carers such as family members. Of course, these tasks indicate the first obstacles to implementing such a programme in remote and rural areas, or regions otherwise deprived of adequate health care facilities: to administer medicines and reduce hospital visits, one first needs medicines, and secondly a sufficient medical infrastructure to support the community based workers. Even with the absence of antiretroviral treatments, one could think of treating opportunistic diseases and symptom control, but this also needs basic medical training, availability of medicines, and institutional support.<sup>vi</sup> The second task, psychosocial support, requires a stigma-free environment, a conducive community in which people living with HIV/AIDS can be supported emotionally and socially. The following sections examine how home-based care systems function in the absence of the above conditions (drugs, healthcare infrastructure, stigma-free supportive community).

### **Case study: community-based care and HIV/AIDS in Migule<sup>vii</sup>**

The case study was carried out in a 'trucker's town', called Migule, on the road between Dar Es Salaam and Nairobi; in the mid-1990s, the town turned into a favourite stop for truckers, traders and other passers-by. It has a thriving drugs economy – based on *mirungi*, a form of khat, a stimulant drug – and the traders and truckers earn extra money by selling goods that 'fall off the back of their trucks'. Most importantly, there is a thriving industry in food, alcohol and sex. The commercial possibilities of Migule (there is also a thriving weekly market where peasants and traders from throughout the region sell their goods) attract not only many visitors, but also many people from the nearby mountains who seek an alternative income to substitute the diminishing agricultural possibilities.<sup>viii</sup> These agriculturalists contribute to the diversity of Migule: all three main religions are well-represented in the town, along with a wide range of people from different ethnic groups. Migule is thus a typical post-colonial settlement with few strong ties that would bind its inhabitants on the basis of culture and custom.

The parallel economy of sex, drugs and illegal goods is evident but unacknowledged. The participating community-based organisations, the ward and village council representatives, health care personnel or other community members did not inform the research team of these activities in the village. Only the participating organisation of people living with HIV/AIDS was open and straightforward about the situation, and assessed it to be a central concern with regard to the community response to AIDS. The silence about the town's parallel economy is relevant, as it points to the local leaders' failure to take prostitution, illegal trading and the high mobility of people, and of AIDS, into account in their approach to the epidemic. Of course, the connection between illegal and legal economies is far more extensive than meets the eye and will certainly influence the lack of visible action taken against the illegal economy.

#### Infection rates

Official statistics show that in 2002, 5.5 per cent of pregnant women who attended the government dispensary in Migule were HIV-positive -a low figure in comparison with many other places, and even compared to the national rate of an estimated 7 to 13% (TACAIDS 2004). This low figure will influence local leaders and the level of urgency they feel is necessary in addressing HIV transmission in Migule, especially in a country with one of the highest malaria cases around the world. However, there are many indications that this 5.5% prevalence is not a very reliable figure. For example, of those persons admitted for non-HIV related illnesses in the regional hospital, almost half were tested HIV positive in 2005.<sup>ix</sup> And there are many other estimates of between 5.5% and almost 50%. Antenatal tests are, of course, not necessarily representative of the general population.<sup>x</sup> According to the medical practitioners in Migule town, few people test for HIV, but many are suspected of having died from it. Official national estimates also show an expected 80% of underreporting of HIV/AIDS cases (URT 2004; Mfangavo 2005). Of course, many women who work in Migule, and many men who use their services, do not live in the town; they are passers-by and go elsewhere as soon as they get ill and need care, or when

business is slow. This is the untested danger group that needs extra attention. Thus, even if we assume that the HIV prevalence rate is 5.5% for Migule inhabitants, then we still have to take account of those with whom the virus travels.

However, there is no special programme directed at clients and sex workers in Migule, although NGOs have organised several *ad hoc* seminars and information days. Neither the government nor the influential Churches have intervened (although faith based organisations organise micro-credit for women in order to provide them with an alternative to sex work). Interviews showed that negotiating condom use is difficult and not always given priority among sex workers.<sup>xi</sup> Although condoms are readily available in local shops and guest houses, and are also affordable, unequal gender relations, the ambiguities of risk and trust (Bujra 2000), and the bifurcation of risk and pleasure (Parikh 2005) prevent consistent condom use among sex-workers and their clients. In addition, among Tanzanians, the conflict between the state's insistence on condom use and many local religious institutions' rejection of the same has created widespread confusion about condom safety and moral legitimacy. Thus, in the absence of targeted prevention policy, Migule's commercial sex sector continues to thrive, putting its inhabitants and visitors at great risk.

The story of Elisa and Mrs Majogo is highly influenced by the structures of poverty and inequality in which many Tanzanians live, but also of the peculiarities of a trucker town: Elisa's three children were conceived by three different men who have all disappeared from the scene. She still tries to use the town's economic structures by selling food to the passers-by, but that is constrained by the stigma attached to being HIV positive and having no husband. That could have provided an incentive for her to conceal her health status, but, she took the decision not to do so as that would have deprived her of the support available. Mrs Majogo, in turn, prefers to cover up the activities that are going on in the town and which influence the incidence of HIV/AIDS. Although she is a community volunteer who helps AIDS patients in her town, she is not prepared to talk about sex, and less so, commercial sex. Although this might not be directly a problem, indirectly this implies that she harbours a prejudice towards people living with HIV/AIDS on the basis that they must be sexually promiscuous, and therefore, to blame for their situation. In a roundabout way, Mrs Majogo also benefits from the support structures: there is social capital in being a community worker, she maintains strong networks with community and district leaders, and, if we believe Elisa, she might be siphoning off food baskets for her own benefit. So the question is: how does Mrs Majogo and her peers combat AIDS and how useful is that?

### **Wanawake: a grassroots women's organisation against AIDS**

Mrs Majogo is the president of a women's organisation in Migule, called Wanawake, which is a branch of a regional NGO. Wanawake was set up in the early 1990s by Tanzanian women based in the regional capital with the objective

to fight AIDS from a women's perspective.<sup>xii</sup> Both a maternalist position – women as care takers – and a feminist position – empowerment – formed the point of departure for Wanawake. Today, the organisation has a considerable regional profile, receives funding from international institutions and maintains a strong network with hospitals, universities, and, although to a lesser extent, governmental institutions. Wanawake assists approximately 200,000 people in the region (of an estimated population of 1.4 million), and they can count on some 700 volunteers and around 15 paid staff members. Their head office is based in the regional capital, but Wanawake counts on 76 community based organisations, run by volunteers, and six district offices directed by (paid) coordinators. The organisation offers information, organisational support, testing and counselling services in the regional capital, and on a community level it also offers orphan support, home-based care, psychological and, since 2003, food support for poor families affected by AIDS. This is delivered by the WFP, and distributed by local Wanawake branches.

Whereas the main programme in the regional capital functions well, with professional Voluntary Counselling and Testing services and paid staff to manage, lobby, and organise activities and training programmes, this study found that local branches struggle to keep up. The 76 local branches are led by volunteers in urban neighbourhoods, rural villages and small towns such as Migule. These volunteers are often drawn from already active community members: they often played a role in local government, in faith-based organisations, or in their own local women's groups before joining Wanawake. Joining Wanawake offers them a wide regional and even international network of information and resources for activities that they might have been developing already. On an individual level, personal motivations to participate in community-based activities in general, and Wanawake in particular, also play a role. As we will see below, these individual motivations are central to the success of the studied community-based activities.

As I indicated above, the local branch of Wanawake in Migule is led by Mrs Majogo, who is a school teacher and who is well connected to the village's leadership, including its only qualified physician. In addition, Wanawake-Migule has twenty women members, of whom two are professional nurses. Several men in important positions, i.e. the physician, and representatives of the Ward and Village committees, are honorary members. Interviews and participant observation showed that the chairwoman's participation in this organisation was strongly linked to status capital on the one hand, and to the possibility of skimming off a bit of the 'loot', on the other. It was not only Elisa who resented Mrs Majogo for her role. Visited beneficiaries' responses to Mrs Majogo alternated between personalised gratitude and fear. This was particularly apparent with regard to the food distributions. Conflict between the leadership of Wanawake in Migule and the beneficiaries focused on selection procedures for beneficiaries of the food baskets and on the 'indivisibility' of household portions. WFP policy stipulates that each selected HIV-affected family should receive one

complete (indivisible) food basket which provides that family with flour, cooking oil, maize and beans for one year.<sup>xiii</sup> Selection procedures of beneficiaries start with WFP choosing a partner organisation in the region. They do so based on official registration, the organisation's ability to provide complementary services to the beneficiaries, and on the recommendation of local authorities. In the studied region, WFP selected Wanawake. Selection of individual beneficiaries is based on household food insecurity among HIV-affected families (with HIV/AIDS patients and/or AIDS orphans). Food insecurity is determined first by the ward council and the sub-village leaders, who provide a list of the neediest persons in the community. This list is made shorter by the local Wanawake leadership, who make a selection of people who have applied for food support, who have tested HIV-positive, and/or who care for orphans. This is still too long a list. Therefore, the local Wanawake representatives shorten the list by judging who is most needy. This is contentious as such decisions are not based on rules or controllable selection procedures, but on personal judgment. It is this stage in selection that generates conflict.

In 2005, there have been three answers to the protests of the beneficiaries who felt let down (justified or not): 1) the local Wanawake leadership tried to divide the portions further in order to give more families a little. This generated further conflict among those who did not receive their fully assigned portions. In addition, the local leaders have tried to shut up complainants by threatening to cut them short. 2) The Wanawake district leadership has involved a third party in the selection of beneficiaries (apart from the Wanawake local branch and the local authorities), namely, representatives of the organisation of people living with HIV/AIDS (discussed below). Whereas this has helped to reconstruct trust at the district level, it has not solved the actual collaboration between these parties as they do not trust each other. The fact that both organisations contain beneficiaries as well as community workers furthers the tensions between individuals. 3) Wanawake regional leadership, i.e, the headquarters, has called for the district and grass roots leaders to join a course on selection procedures. While this should be helpful, the situation had not changed after the course. On the day of distributions, the Wanawake district leadership had to intervene as the conflict between recipients and distributors had not found an acceptable solution to allow for the distributions to continue. Despite the efforts, no trust was consolidated between distributors and beneficiaries in Migule. The role of Mrs Majogo is crucial in this conflict. She personalised distribution, creating a patron-client relation with beneficiaries, she spoke badly of individual beneficiaries to local leaders, she did not involve the other nineteen members of her organisation in the distribution (although two or three of the members seemed to be fully aware and supportive of Mrs Majogo's actions), and she gave a strong impression of skimming off the portions for her own benefit. In sum, Mrs Majogo seemed to use Wanawake and the WFP food baskets as a means to maintain and expand a network of dependants throughout the town. Although this experience refers to only one person and her small circle of allies, anecdotal evidence from neighbouring towns who took part in the same food programme

suggested a more widespread problem. The response of WFP and Wanawake headquarters also suggested an awareness of a wider problem. Unfortunately, our example shows that local hierarchies and expectations are difficult to alter through further institutional intervention by WFP and Wanawake headquarters.

Distributing food is not all that the community-based Wanawake branches do. According to the constitution of Wanawake, home-based care, HIV prevention, and orphan care are the central tasks of the local branches. In Migule, the work done by the volunteers included community work such as raising money for events or buildings. In 2004, the group successfully raised money for an orphan house and supervised its building. In the area of prevention, the volunteers distribute centrally developed materials such as posters and leaflets. In the area of home-based care, the volunteers might visit a neighbour, help ill and poor neighbours with small foodstuffs, or, in some cases, inform health care personnel of any problems. However, there is little structure or continuity in such activities. According to the volunteers themselves, this has to do with busy schedules and a lack of training and medicines. Although medicines are indeed scarce, training should not have been a problem. With two professional nurses and a physician member of Wanawake, the capacity should have been there. This suggests that there might be reluctance among the volunteers to carry out home-based care.

Whereas such reluctance may have many causes, the Wanawake leadership's behaviour in Migule suggested disinterest in the HIV problem. The food they distribute gives them power and control over certain impoverished groups in the community, and gives them a strong grip on other local initiatives in which people can be beneficiaries as well as activists. The leadership's attitude towards people living with HIV/AIDS is maternalist in a negative sense; there is little to no sensitivity or compassion with victims but there is a strong (moral) hierarchy between provider and beneficiary. This hierarchy is constantly emphasised by the behaviour of the leadership of the Wanawake branch, and is expressed in terms of education, poverty, and health status. As such, whereas participation of local community members such as the Wanawake volunteers is supposed to guarantee effectiveness and ownership of the WFP food programme (Okondo and Newton 2000), in fact it may reinforce hierarchies between those formally seen as 'equal members' of an organisation, and, in extension, between what is ultimately seen as relationships between 'client and worker', or staff and the poor and powerless (Bujra and Mokake 2000: 164-165). These hierarchies severely jeopardised the needed confidentiality and trust between the volunteers and the beneficiaries, and instead, increased distance between them. Thus, while Wanawake is doing very well on a regional level, where specialised and paid staff work together with volunteers and people living with HIV/AIDS in a transparent and accountable manner, the story of Migule suggests that local Wanawake branches struggle with hierarchy versus solidarity, with leadership and prejudice, and with a lack of professionalism.

### **Second community initiative: Village health workers**

In 2004, the Tanzanian government commenced the installation of its new decentralised multi-sectoral framework against AIDS (TACAIDS 2003; Mfangavo et. al 2005). As part of this programme, each village had to appoint a representative and inclusive Village Health Committee (VHC), which had to coordinate with their ward and district health committees on health issues, particularly on establishing a health care and prevention framework to fight HIV/AIDS locally. To breach the gap between a deficient health care system and the population, especially in rural areas, each subvillage, or neighbourhood, was to select two Village Health Workers to support the formal health care system.

This scheme was not implemented at a national scale; however, in Migule the international NGO World Vision (and funding from the European Union) took the initiative to support a Village Health Workers system as they had done with previous schemes. Village health workers have been active in Migule since the early 1980s. Throughout the years, international NGOs and faith-based organisations trained community members to support the activities of the governmental health care services. For example, Marie Stopes, an international organisation promoting reproductive health, trained several community-members to promote family planning and maternal health care in 2000 (Marie Stopes 2000).<sup>xiv</sup> The Catholic Church was also active from an early stage, while the trained health care workers often worked closely with local state services.

In 2004, the fourteen appointed Village Health Workers (VHWs) were mainly members of the dominant ruling party (Chama Cha Mapinduzi – CCM) and all rotated community tasks within the local political hierarchy. They are, have been, or will be, elected members of the Village Council or Ward Committee; they are village elders and ten-cell leaders, members of school boards and elders of faith-based organisations. This means that their community participation forms part of prescribed and expected activities for community leaders, an almost compulsory voluntarism (Marsland 2006). Thus, although the VHW were formally selected by their sub-villages, and enjoyed the trust of their neighbours to carry out community tasks, their political role in the community does not necessarily guarantee confidentiality in sensitive matters such as HIV/AIDS.

The village health workers have two major tasks: home-based care for the chronically ill and hygiene and sanitation advice. According to the village health workers, the last task works reasonably well: they make sure that all their neighbours build toilets in their houses and care for their garbage processing. This is a neighbourhood activity which is bolstered by the local militia.<sup>xv</sup> The practical and concrete nature of such advice does not allow for too much ambiguity. Providing home-based care is more complicated, as there are issues of confidentiality, trust, and stigma, and (a lack) of time, training and medicines.

The prominent and public positions that the VHW occupy in their communities might not be beneficial to the required discretion implicit in HIV/AIDS care. Families with AIDS patients often do not want the neighbourhood to know, and

HIV positive people do not want the neighbours to interfere. For example, in one instance a community worker went to visit a woman in Migule who the community worker suspected to be bedridden – as she had not been seen out for a while. When he tried to enter the house, the woman's son not only stopped him, but violently kicked him out and warned him never to come back again with stories about his mother. The son claimed his mother was fine and they did not need any help. On a later day, the woman called the community worker to come in as she did want to know what kind of support she could seek. She was indeed bedridden, very ill and in pain. The community worker offered to look for pain killers for her, but she said her son would not allow her to take medicines from them. The community worker tried to talk with the son on different occasions in the hope he would come to his senses. There was little progress in this effort. As Maud Radstake (2000), Felicity Thomas (2006), and Nnko et. al. (2000) conclude about home-based care in Ghana, Namibia and Tanzania respectively, secrecy is paramount in families struggling with HIV, and often prevents the involvement of outsiders in home-based care. The village health workers do not have much to offer either – even pain relief was not always available. Just as the Wanawake volunteers did, the village health workers said they sometimes tried to comfort people by bringing small foodstuffs around to families they knew were struggling, but they would not talk about HIV, as this was too sensitive.

First, however, the village health workers' complaints about training deserve a further scrutiny, especially since 'the number of training courses' seems to be an important mechanism to measure achieved capacity building among World Bank project evaluators (Kumar 2005: xii). In the interviews held with village health workers in 2005, all indicated that they lacked the knowledge to do their jobs well. Nevertheless, training courses have been offered since the 1980s and often involved the same people who are today village health workers. This would mean twenty-five years of health care training of a small group of community-leaders, and thus, a highly skilled team. Looking at the subjects offered and the institutions involved, however, suggests that the content and focus of such training programmes change according to not only paradigm shifts in international development, but in ideological background of the supporting institution. As such, in these twenty-five years, several of the village health workers had received training in hygiene offered by Caritas, family planning from Marie Stopes, home-based care and HIV prevention from World Vision, and later the same from the district government (financed by the European Union). Normative notions embedded in capacity building interventions might impede the effectiveness of offered training, especially in relation to prevention strategies. It could well be that ideas about what development is, hygiene, family planning (versus, for example, birth control or reproductive health), and safe sex differ so much between organisations and moments in time, that community workers do not accumulate knowledge, but rather, change perspectives. In addition, as Maia Green suggests, that what is seen as 'capacity' and, explicitly, 'good' local governance, in the eyes of international development organisations, is not necessarily compatible with a) the desired skills among the selected workers,

and b) the existing power structures and communication lines (2006: 5). Such an analysis is provocative and further suggests that the failure of subsequent capacity building schemes set up by different organisations to actually build sustainable capacity needs further attention.

Another factor that impedes well-trained volunteers is, according to several appointed and trained village health workers, the 'Training of Trainers' schemes. Volunteers are often expected to transmit their required knowledge to their fellow community workers, but often trained people do not have the skills, time or tools to teach others. Hierarchy between participants also plays a role in the lack of success of such schemes; as was clear among the Wanawake community-workers, not all trained people are prepared to share their knowledge. In sum, while training courses offered might empower the trained with skills and knowledge, this capacity is not enough, or sufficiently appropriate, sensitive, or community-wide to have provided for well-functioning home-based care carried out by state appointed, volunteering, village health workers.

Despite the difficulties, village health workers play an important role in the community's health care system: according to the nurses working at the government dispensary of Migule, village health workers provide, more than anything, information to the health care personnel about potential patients. Village health workers are often aware of what is going on in their neighbourhood. This is not necessarily due to their role as health workers, but due to their role as neighbourhood representatives –ten cell leaders, elders, clergy- in other institutions. Although most people do not want to talk about HIV/AIDS and are reluctant to call in the help of health care personnel or volunteers, these leaders are well-connected to the population and are often aware of problems. They can warn the nurses at the dispensary, or advise people when they should go and see the doctor. Thus, the socio-political position of village health workers as neighbourhood leaders can be both an advantage – they know what is going on and can advise dispensary personnel and patients – or a disadvantage since people might feel more reluctant to share their worries with regard to HIV/AIDS because of stigma.

### **Kikumi: People living with HIV/AIDS**

The third community-based group studied, Kikumi, consists of a group of twenty mostly people living with HIV/AIDS, all resident in Migule and self-organised in 2003 in the light of examples elsewhere. Two nurses from the government dispensary also joined Kikumi. The group claims it includes both HIV-positive people and non positive people, but it is not clear who is and who is not HIV positive. All members are affected one way or the other. Kikumi is different from the above discussed community-based worker schemes as the volunteers' dedication to the objectives set is complete. The group looks for funding from both governmental and nongovernmental sources, works with local authorities and other community based groups, and maintains an increasingly strong

regional and national network of people living with HIV/AIDS. The group provides vocational courses and work for orphans – they have a workshop for tailoring and carpentry – they do outreach work, prevention work, condom distribution, and, indeed, home-based care. Kikumi has (limited) access to donated medicines for opportunistic diseases – mainly antibiotics and painkillers – and they have basic medical and dietary knowledge and, above all, good connections with the local and district medical community.

Just as in the case of the other two groups, home-based care does not account for much; it seems a term imposed by governmental and nongovernmental institutions that community organisations have adopted for the purposes of funding. Without treatment, basic drugs or even plastic gloves that can be used by community-based workers and family carers, home-based care means visiting a neighbour and perhaps helping out economically or having a chat. However, in the case of the PLHA, and despite these limitations, Kikumi appears to have a positive impact on the HIV/AIDS response in Migule in large measure because they are able to identify with the beneficiaries.

HIV-positive people and AIDS patients seem to trust the Kikumi activists, but they do not trust the dispensary personnel or the Wanawake women. This is, of course, the result of the identification factor between HIV-positive people and the lack of stigma amongst themselves, i.e., the strong relationship between provider and beneficiary. Stigma, blame and shame are very tangible in the relation between beneficiaries and the other two community-based organisations. With Kikumi this is absent. For them, activism is a lifeline, it is a reason to live and provides for a future that is otherwise precarious. For example, Mr Msinga told about his desperation when he tested positive for HIV; he stayed in bed for weeks, without sleeping. He got out of his depression after speaking with an organisation of people living with HIV/AIDS in the regional capital and decided to become involved in community work related to HIV/AIDS. He joined the organisation in the regional capital and founded a similar one in the capital of the District. Subsequently, he participated in founding Kikumi in Migule. Mr Msinga suggests that his activism not only helps to fight AIDS in his community, but that it also gives him a reason to live. In similar vein, Anna Matumika, a widow in her late twenties with two children, explained that when you are tested positive for HIV infection, you experience a *premature death*, you are still alive and relatively healthy, but you cannot do anything anymore because people will shut you out and take away your responsibilities. You can only think about your misfortune. People living with HIV/AIDS are physically threatened by HIV and then 'prematurely' neglected by their social networks often including their own family (on social death, see also: Robins 2005). HIV-positive persons are seen as a burden instead of a contribution to their families and community. For example, Flora told us that her parents ostracized her and her children at first. However, as Flora really needed them after her husband died and she was tested positive, she pleaded with her parents after which they took her and her children in. However, now there is no work for her, as nobody wants her. Her idleness drove

her crazy and she felt very depressed. Being part of the group of HIV-positive people Tumaeni, in the District capital, helped her to be busy, make plans, and feel supported by other people living with HIV/AIDS.<sup>xvi</sup> Activism regenerates the social life of people living with HIV/AIDS and perhaps even helps to create an alternative community (Manchester 2004).

There is a second dimension to this activism which relates to children. By working to set up structures of care for orphans in the form of education and health care, activist PLHA are also providing for their own children. Most members of Kikumi had small children and took care of several orphans left behind by friends or siblings. They were very concerned about the futures of these children. In that sense, Kikumi's collective interest in HIV/AIDS prevention and care is more productive than activities of the more traditional leaders of the women's organisation discussed or the village health workers. Thus, even if institutional factors are important for the effectiveness of community participation, the collective motivation for participating is likewise central to the success of such interventions.

The status of the Kikumi group in Migule is ambiguous. On the one hand, some leaders of Wanawake dismissed them as being uneducated HIV positive and promiscuous poor people. Their lack of completed secondary education, of leadership positions within the community-structures, and of the ability to speak English all contribute to their low status (Mrs Majogo, chairperson of Wanawake, claimed that the chairperson of Kikume 'was at least a bit more sensible', as opposed to other members of the group. Kikume's chairperson, Mr Msinga, is a very charismatic leader and successful on a regional and even national level. Although he did not finish secondary education, he is obviously the best educated of all Kikumi-members). Their links with the transit population of Migule might contribute to the hostility they sometimes receive. Kikumi members actively engage with the more mobile population of Migule and have organised prevention talks for sex workers. Several of Kikumi's members, such as Elisa, engage in selling foodstuffs to truckers. Elisa's children are probably the product of transactable sex – as Mrs Majogo explained, she got her children 'off the street' – although that does not necessarily mean that she worked in one of the many guesthouses. Kikumi members' entrance into the public space, while admitting HIV-positive status and actively campaigning for HIV-awareness within the community's institutions, did not always receive approval either. The first school education talks Kikumi organised in the community were, for example, received with physical aggression on the part of some parents. The orphans who receive training with Kikumi members are often stigmatised, and the girls in particular suffer sexualised aggression from men. All Kikumi members admit that moving about through the village requires courage, and several members have decided to keep as private as possible. However, as the Kikumis themselves indicate, despite the public name-calling they often receive, most community members are starting to get used to their presence. Among many local organisations, Kikumi is increasingly recognised as important. During our

research activities, Kikumi secured a credit deal with a district level agricultural NGO to start income generating activities and was talking to several other district-level institutions for further financial support. They are respected for their activism and dedication, and, at community level, especially for their visible and increasing success with donors.

A connection between Kikumi, the village council, Wanawake, and the village health workers exists, but rests largely on the friendly persistence of Kikumi's leadership. These relationships are, at best, formal, and at worst, unequal. Wanawake has a grip on Kikumi members through the WFP food distributions, while the professionally-trained dispensary nurses – one of whom is a member of Kikumi – are more important to Kikumi than are the village health workers. The political leadership of Migule accepts and supports Kikumi by 'not obstructing them in any way' (as the village chairman indicated to me). These relationships emphasise the ambiguity of Kikumi's presence in the community. In the meantime, quietly, Kikumi members have established large networks of people living with HIV/AIDS throughout the region, accumulated (potential) donors and supporters, improved their access to resources through this support, and expanded their prevention activities to smaller rural villages rarely reached by other community-based organisations, NGOs, or district and regional government activities. If there is a community organisation that knows what is going on and how many people might be affected by HIV/AIDS in Migule and surroundings, it is Kikumi.

Despite such relative success, the increasing support available for people living with HIV/AIDS and their families has, in some cases, generated envy over access to resources. Several informants indicated that those who receive anything, however little, because they are affected, are often met with rejection and even animosity from other family members and neighbours. For example, one of our informants, Mrs Msinga, wrote in her diary (which we requested her to write) how she was often treated badly by neighbours and family members because she and her husband are active community volunteers and receive WFP food support. Both Mrs and Mr Msinga are HIV-positive and take care of their own two children plus three orphans left behind by friends. Like many such families, they can use every support available to care for themselves, their children and orphans that are often partly or completely dependent on them. The sad thing was that the family members of the orphans in question refused to care for the children, but now scold their voluntary parents because they believe that they 'receive lots of money from a sponsor abroad'. Mr and Mrs Msinga are accused of opportunism because they had the courage to take up more children than they could handle. The children in question – both in their early teens – respond to these family tensions with aggression towards their adopted siblings, which, in turn, creates resentment and a regime of physical punishment on the part of Mrs Msinga. At the same time, given the reputation of being helpful and generous on the one hand, and the existing belief that the Msinga's receive

funding from outside, more children are sent to the Msinga's by their carers in search of help.<sup>xvii</sup>

Despite such conflicts – which are strongly related to a culture of aid, to HIV-related stigma and fear, and to the existing battles over access to resources among a generally poor population – and despite the lack of consistent institutional support, Kikumi is capable of providing some home-based care. It is also capable of doing outreach work, of organising prevention seminars among rural populations, youth and, as the organisation is planning for the near future, more regularly among sex workers. The actual success of such work in reducing HIV transmission and changing sexual behaviour is still to be seen and, in the light of a continuous lack of drugs, their version of home-based care is palliative. Nevertheless, their increasing visibility and their persistence in raising awareness among both HIV positive people and other community-members can only be positive.

#### *Understandings of home-based care*

All three community-based programmes studied included home-based care as a formal objective. Above all, this indicates the awareness that these community-based organisations have of international paradigms with regard to HIV/AIDS. For the village health workers and for the Wanawake volunteers, home-based care means 'counselling', a concept that includes dietary and hygiene advice and is sometimes complemented with carrying out small domestic tasks or handing out small foodstuffs. Emotional or social support does not necessarily enter in this definition (although it does on paper). However, in practice, these two programmes involve very little home-based care. For the Kikumi members, home-based care is still less defined. The volunteers assume a caretaking role towards each other (emotional, material, social care and exchange of useful information) and an outreach role towards fellow HIV/AIDS sufferers who have not gone public (yet). Sometimes Kikumi administers medicines to treat opportunistic diseases, which they distribute with the help of the two specialised nurses at the government dispensary who are also active members of Kikumi. However, this depends entirely on the availability of such medicines. The Kikumi members do not separate home-based care from other tasks – such as prevention activities or outreach – but do recognise its formal use: officially, they have a home-based care representative, just as the village health workers and Wanawake have.

As such, a formal institutional network of donors expects the community-based workers to carry out home-based care, while at a local level such an expectation is not always realistic. Stigma, existing hierarchies between community-based workers and beneficiary and the absence of medicines, prevents consistent home-based care. The medical assistant at the government dispensary – the person who should be aware of the home-based care programmes in Migule and who was responsible for several training programmes in voluntary counselling and testing and home-based care, financed by international donors – could not

mention any patients under the care of the village health workers, or under the long term care of his dispensary. As he explained, how was he expected to follow up on unwilling HIV/AIDS patients who did not want anyone to know their status? Similarly, Maude Radstake observed (2000) that the tension between the need for openness implicit in home-based care and the strong wish for secrecy among AIDS patients and their families, makes home-based care a very private and covert matter. For volunteers or even health care personnel, this is often an impossible space to enter.

In sum, it is very difficult for medical personnel in resource-poor settings to perform home-based care, or to support voluntary staff such as the village health workers or the Wanawakes, when medicines and treatment are not consistently available, and stigma prevents a majority of people of being open about their (or their family-member's) health status. Voluntary staff can contribute to the distribution of knowledge with regard to hygiene and dietary issues – although both are difficult to promote among households that experience a downward spiral of poverty as a result of AIDS. Community volunteers provide health care authorities with information about the health in their neighbourhoods, as they often do know what is going on. However, the secrecy and stigma related to HIV prevents most community-based workers from actually performing home-based care activities; both because community-based workers might be prejudiced towards AIDS patients, and because people fear possible prejudice and thus self-stigmatise. Families with AIDS patients often experience a range of social, emotional, and economic problems that are not easily addressed by 'outsiders' (Thomas 2006, Chimwaza 2004). At the same time, the case studies suggest that alternative communities such as the networks of people living with HIV/AIDS might be able to deliver care and establish the necessary trust with AIDS patients and their families that is needed for socio-psychological support.

### *Conclusion*

The case studies of three different models of community based care, based in a trading town on a busy international route, showed, first of all, that the peculiarities of a trading town affects HIV-prevalence, but not necessarily its official HIV-prevalence statistics. The testing of pregnant women who attend the antenatal services of the dispensary excludes the mobile men and women with whom the virus travels. Other pregnant women, such as Elisa, might not use the dispensary because of poverty or indeed, fear for testing. Women beyond reproductive age, such as Elisa's mother, also jump the scrutiny. Nevertheless, the relatively low prevalence rate of 5.5, based on antenatal tests, might prevent the local government from taking HIV/AIDS more serious. In addition, Migule's economic growth is largely dependent on the fact that it is a popular trucker's stop. In Migule, it is not only mobile women who make their living from sex-work; local women such as Elisa also 'benefit' (the benefits of sex work in times of AIDS is highly ambiguous, of course.<sup>xviii</sup>), and observation leads to the conclusion that local men also use the services of sex workers. In addition, local authorities profit from the business of sex, drugs, illegal trade, food and drink through the

levying of legal and illegal taxes, and from the general increasing economic activity and importance of Migule. Migule is indeed a growing community; however, it is not based on solidarity, ethnicity, history or tradition, but on economic activities that clash with the demands of an effective HIV/AIDS response. This makes Migule a particular case which may explain the negligent attitude of the local government. At the same time, the issues discussed above may not be that specific to Migule, and may, rather, serve as a useful case study of constraints in community-based worker systems and HIV/AIDS care and prevention.

This paper examined the interlinkages between institutions, community-based workers and beneficiaries and how such relationships positively or negatively influence the delivery of basic services to HIV affected populations at community level. All interviewed community-based workers, from the three organisations, reported a lack of institutional support. The community organisations carrying out care and prevention felt they needed more training, resources (gloves, drugs for pain relief and opportunistic diseases, and ARVs), and supervision to support HIV/AIDS affected families. The web of institutions supporting community-based initiatives is often much larger and more complex than it seems at first sight. Each organisation studied received or had received training, financial support, and material support (goods) from a range of institutions, both international and national NGOs, state institutions (TACAIDS, district government, health care services), and religious organisations. None of the organisations studied was supported for longer than three years by the same institution. The organisations studied, thus, also changed name, direction, and sometimes membership: both Wanawake and the village health workers had existed in other forms previous to their present day form. This high turnover of supporting institutions reinforces the lack of actual resources, and the feeling of a lack of support among CBWs. The lack of national coordination of an HIV response and coordination of interventions – despite the existence of a framework to do so (Mfangavo et. al. 2005) – and the lack of a local formulation of a coordinated HIV response – despite the existence of a committee to do so – leave community-based organisations to fight in an environment of unclear responsibilities. This lack of coordination and clarity in the AIDS response also makes competition over scarce resources more likely, and thus, feeds into further fragmentation of local interventions.

The relationship between community based workers and beneficiaries was influenced by the stigma attached to HIV/AIDS, obstructing plain communication and openness between community worker and patient. However, tensions between community members and community-based workers were also related to the influx of external resources and support for AIDS affected families, reallocated by community-based organisations. In the case of Wanawake and WFP food distributions, the tensions were largely generated by a lack of transparency and accountability of Wanawake-Migule with regard to selection criteria for beneficiaries and destiny of funds or goods obtained. Mistrust of the community workers responsible for distribution was furthered by the authoritarian

and clientelist attitude of the chair person of the organisation, Mrs Majogo. Although this could be a specific local problem, not relevant to wider issues of community-based worker systems, this seems not to be the case. Mrs Majogo was elected by the members to be long-term chair person of Wanawake in Migule because she has the connections and the authority to do so. The 'democratic' system of two-yearly elections of leaders (as required by the head quarters of Wanawake) does not always lead to satisfactory representation. People often elect long-term leaders with the best connections and the highest education, which are not necessarily the most just leaders. Existing structures of authority and power are reproduced in community based organisations, and clientelist networks reinforced through these organisations.

This brings us to the second question examined in this paper: how do personal interests of community-based workers influence their performance? Personal interests and motivations are often overlooked in institutional design of community-based workers systems. Nevertheless, as these are voluntary activities which require dedication and sensitivity, people's motivations do matter. As there is no pay for doing these jobs, other incentives encourage people to participate. The three studied community initiatives show us three models of community participation. First, there are the women who create their own space parallel to men's organisations. Women's participation in collective action to care for other community members, often a specific group of vulnerable people (the poor, single women, orphans), and, simultaneously, to create an all-women space to counter the overwhelming presence of men in the public space, are not unique to Migule, Tanzania or to Africa. Wanawake fits such traditions, while also (especially at the regional level) claiming a feminist standpoint that aims to change the structures of gender inequality. The organisational aims and objectives, however, do not always explain individual drives. Mrs Majogo, and several of her colleagues, clearly appealed to status capital, enforcing their positions as well-educated leaders in Migule. Rumours had it that Mrs Majogo also gained material benefits from participation in Wanawake – through skimming off food baskets, or through other means. Whether such accusations were based on the truth is perhaps less relevant; fact is that her attitude and the lack of transparency and accountability generated conflict.

In the case of the village health workers their position in the community as neighbourhood representatives influenced their possibilities as home-based care givers. Whereas their appointment as health workers was taken for granted by both the appointees as well as the neighbours who selected them, and reinforced their position as elders in the community, this 'political' position did not necessarily improve their possibilities to reach out for HIV/AIDS patients and their families. The central position village health workers had did facilitate the connection between the neighbourhoods and the dispensary, however, as the volunteers were often aware of occurring health problems.

In the case of the members of Kikumi, their positions as HIV-positive people made their position within the community often suspect, while, at the same time, facilitating the possibility for other HIV-positive people or AIDS patients to open up to them and seek support. The possibility of identification between beneficiary and community based worker is the strength of Kikumi collective action. The members' direct identification with the problem and their personal necessity for intervening in order to give meaning to their otherwise future-less lives, make them highly productive and hopeful.

In his comments on the OED evaluation of World Bank funded community-based and driven programmes, Robert Chambers observes that underestimated or hidden externalities to such programmes could mean that such interventions do more harm than good (Kumar 2005: 153). The above examples suggest that hidden externalities such as increased conflicts over resources and the affirmation of an aid culture are enmeshed in the clientelist character of the relation between community-based worker and beneficiary – as opposed to empathy and solidarity as in the case of the initiative of Kikumi activists. The availability of food support gave power to the distributors and therefore confirmed hierarchy within the community. Whereas this study strongly suggests that poor people *are not* empowered by community participation in food distribution, the open question is whether such clientelism is to be preferred over nothing at all. There also might be a possibility to improve trust between beneficiary and distributor by selecting the distributors differently (instead of focussing selection on the beneficiaries). Whereas individual selection of local distributors would be a difficult and perhaps impossible task for WFP, it might be possible to instruct distributors differently, or to reconsider the selection criteria for distribution networks.

Another area in need of further thinking, if not further research, is the question of how external involvement in communities disrupts relationships within these communities. Whereas it seems clear that poor families affected by HIV/AIDS, such as the ones involved in this study, can use any help they can get from inside the community or external actors and institutions to survive, this support often disrupts the existing social safety nets. For the diary-writer who observed how she was resented by family and neighbours not only for being HIV-positive, but for receiving support for having it, aid negatively influenced her position in the community. The gossip about her motivations for supporting orphans also reflected on the children in her household, severely jeopardising the peace amongst them. Again, perhaps this is preferable over no help at all. However, the social tensions that fragmented community-based interventions are likely to engender are often entirely overlooked by the policy makers who decide over them. The participation of community members in facing the AIDS epidemic is, of course, essential. However, as a result of the emphasis on community-driven development in a framework of the neo-liberal logic of decentralisation and privatisation the institutional support given to communities seems unclear and little consistent, furthering the possibility for social tensions.

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## Notes

<sup>i</sup> I thank Frances Cleaver, Anna Toner, Paulo Drinot, Janet Bujra, and an anonymous reviewer for their readings of earlier drafts of this paper.

<sup>ii</sup> Whereby cost-effectiveness is understood as maximum result with a minimum of cost.

<sup>iii</sup> A more detailed report on these case studies can be found in Boesten 2006.

<sup>iv</sup> One could argue that, during the 1980s and early 1990s, HIV/AIDS activism strengthened the gay community in the West, thereby releasing solidarity which also made extensive buddy and HBC (home-based care) networks possible: Howell (1991), Weeks, Aggleton, McKevitt, Parkinson, and Taylor-Laybourn (1996).

<sup>v</sup> Several authors argue that under the influence of AIDS, the moral economy in which the discourses around sexuality develop result in changing sexual taboos and sexual learning, and an, as yet unresolved, tension between risk and pleasure, and between biomedical and cultural interpretations of sexual practice (Setel 1999, Parikh 2005). As long as such confusion around sexual taboos – and gender relations – are not solved, HIV might continue to spread, and stigma continue to be imposed on PLHA (people living with HIV/AIDS).

<sup>vi</sup> HBC programmes in South Africa provide a different example. See CDD (Community-Driven Development) Working Papers nos. 4 and 10 (Mdhuli 2006, and African Institute for Community-Driven Development 2006); and also Uys (2002). Of course, the issue of providing anti-retroviral treatments (ARTs) for free to African populations is recently being given new attention. By the time this paper goes to print, Tanzanian hospitals are providing free ARTs.

<sup>vii</sup> All names of places, persons, and organisations mentioned have been changed for the sake of anonymity.

<sup>viii</sup> Tree-cutting for firewood, climate change, and diminishing water resources has caused population pressure and makes the surrounding mountains and plains increasingly difficult to live from. The poorest -farmers with no land, or no access to water- might barter charcoal and building stones.

<sup>ix</sup> The diary of Mr Msinga quotes (for the same hospital) statistics for the Jan-May period of 2005, 5-7-05. 46% tested HIV positive among hospitalised people is, of course, not the same as 46 % of non-hospitalised persons.

<sup>x</sup> First, not all women make use of the medical services, as many live out of geographical and/or economic reach of services. Second, antenatal tests provide a selection bias (pregnant women) and exclude large parts of the general population, and third, HIV-positive women are biologically less likely to become pregnant (Barnett and Whiteside 2006: 62).

<sup>xi</sup> Gender inequity often negatively influences women's agency to negotiate condom use. Poverty among women makes this worse. On condom use among sex workers in Malawi: Van den Borne 2005; on South Africa: Campbell 2003

<sup>xii</sup> Tanzania is administratively divided into villages, wards, districts, and regions.

<sup>xiii</sup> WFP policy is explained in: the Country Programme Activity Summary, Tanzania, 2002-2006. An email conversation with Assumpta Rwechungura, WFP coordinator, Dar es Salaam, 29/11/05, provides for additional information.

<sup>xiv</sup> Also: interview with Neatness Gideon, Director Marie Stopes district office. These trained community-workers, or peer educators as they are also designated, often drop out, or lose interest.

<sup>xv</sup> Rural Tanzania has a system of militias, established under Nyerere, whereby young men volunteer as community guards parallel to the police system, and are supported by village elders.

<sup>xvi</sup> Group discussion with members of Tumaeni in the District capital, 30-03-05.

<sup>xvii</sup> Mrs Msinga, diary 10/7, 13/07, 14/7 2005.

<sup>xviii</sup> For a discussion on sex work as survival see Van den Borne (2005).

## *Bibliography*

African Institute for Community-Driven Development (2006). Policy Overview: HIV/AIDS Policy in South Africa. CDD Working Paper 4, Bradford Centre for International Development, University of Bradford.

<http://www.bradford.ac.uk/acad/dppc/research/poverty/projects/interlink/papers/>

Barnett, T. and A. Whiteside (2006). *Aids in the Twenty-First Century: Disease and Globalization*. Basingstoke; New York, Palgrave Macmillan.

Beard, V. A., and A. Dasgupta, (2006). 'Collective Action and Community-driven Development in Rural and Urban Indonesia.' *Urban Studies* 43 (9) 1451-1468.

Berman, P., Davidson R. Gwatkin and Susan E. Burger, (1987). 'Community-based health workers: Head start or false start towards health for all?' *Social Science and Medicine* 25(5): 443-459.

Boesten, J. (2005). 'Community-Based Workers and Service Delivery: A Literature Review'. CDD Working Paper 1, Bradford Centre for International Development, University of Bradford.

<http://www.brad.ac.uk/acad/bcid/research/poverty/projects/interlink/papers/>

Boesten, J. (2006). Understanding the interlinkages between individuals, community-based workers, and institutions in community-based HIV/AIDS prevention and care systems, Northern Tanzania. CDD Working Paper 5, Bradford Centre for International Development, University of Bradford.

<http://www.brad.ac.uk/acad/bcid/research/poverty/projects/interlink/papers/>

Boesten, J., F. Cleaver, and A. Toner 2006, Community-Driven Development (CDD) Working Paper Series, Bradford Centre for International Development, University of Bradford.

<http://www.bradford.ac.uk/acad/dppc/research/poverty/projects/interlink/papers/>

Bujra, J., and S. Mokake, (2000). 'AIDS activism in Dar es Salaam: many struggles; a single goal.' In C. Baileys, and J. Bujra (eds) *Aids, sexuality and gender in Africa: collective strategies and struggles in Tanzania and Zambia*. London; New York, Routledge: 153-173.

Bujra, J., (2000) 'Risk and Trust: Unsafe Sex, Gender and AIDS in Tanzania.' In Pat Caplan, *Risk Revisited*, London: Pluto Press.

Campbell, C. (2003). *Letting Them Die: Why HIV/AIDS Intervention Programmes Fail*. Oxford, International African Institute.

Chimwaza, A. F., and S. C. Watkins, 'Giving care to people with symptoms of AIDS in rural sub-Saharan Africa,' *AIDS Care*, vol. 16, no. 7 (2004), pp. 795-807.

Creed, G., and J. Brooks (2006) *The Seductions of Community: Emancipations, Oppressions, Quandaries*. London: James Curry Publishers.

Farmer, P. (1999). *Infections and Inequalities: The Modern Plagues*. Berkeley, University of California Press.

Green, M. (2003). 'After Ujamaa? Cultures of Governance and the Representation of Power in Post Socialist Tanzania'. Paper presented at the Association of Social Anthropologists Annual Meetings, Manchester.

Howell, E. M. (1991). 'The Role of Community-Based Organizations in Responding to the AIDS Epidemic: Examples from the HRSA Service Demonstrations.' *Journal of Public Health Policy* 12(2): 165-174.

Kumar, N. (2005). *The effectiveness of World Bank support for community-based and -driven development: an OED evaluation*. Washington, D.C., World Bank.

Manchester, J. (2004). 'Hope, involvement and vision: reflections on positive women's activism around HIV.' *Transformation: Critical Perspectives on Southern Africa* 54: 85-103.

Marie Stopes Tanzania (2000). 'Report on Base Line Survey and Community Needs Assessment for Reproductive Health Services in Same District, Kilimanjaro Region'. Dodoma.

Marsland, R. (2006). 'Community participation the Tanzanian way: Conceptual contiguity or Power struggle?' *Oxford Development Studies* 34(1): 65-79.

Mdhluli, L. African Institute for Community-Driven Development (2006). Case Study: Community-based workers and HIV/AIDS in Bloemfontein, South Africa Community-Driven Development Working Paper 10, Bradford Centre for International Development, University of Bradford.  
<http://www.bradford.ac.uk/acad/dppc/research/poverty/projects/interlink/papers/>

Mfangavo, C., A. Toner, F. Cleaver, and J. Boesten, (2005). 'A review of policy and practice in relation to water and HIV/AIDS in Tanzania'. BCID/Community Action Working Paper Series (2).  
<http://www.brad.ac.uk/acad/bcid/research/poverty/projects/interlink/papers/>

Nnko, S., B. Chiduo, F. Wilson, W. Msuya, and G. Mwaluko, (2000). 'Tanzania: AIDS Care- Learning from Experience.' *Review of African Political Economy* 27 (86): 547-557.

Ogden, J., and L. Nyblade, (2005). *Common at its core: HIV and AIDS stigma across contexts*. Washington DC, ICRW.

Okondo, Hendrica, and Kate Newton (2000). Summary of report: Gender Assessment of Selected Relief Committees in Marsabit District-A field mission. WFP Kenya-

<http://www.ennonline.net/fex/12/rs5.html>

Parikh, S. A. (2005). 'From auntie to disco: The bifurcation of risk and pleasure in sex education in Uganda'. In V. Adams and S. L. Pigg (eds.) *Sex in Development: science, sexuality, and morality in global perspective*. Durham, Duke University Press: 125-158.

Radstake, M. (2000). *Secrecy and ambiguity: home care for people living with HIV/AIDS in Ghana*. Leiden, African studies Centre.

Robins, S. (2005). 'Rights passages from 'near death' to 'new life': AIDS activism and treatment testimonies in South Africa'. IDS Working Paper, Institute for Development Studies, (251) Sussex.

Setel, P. (1999). *A plague of Paradoxes: AIDS, culture, and demography in northern Tanzania*. Chicago, University of Chicago Press.

Swider, S. M. (2002). 'Outcome Effectiveness of Community Health Workers: An Integrative Literature Review.' *Public Health Nursing* 19(1): 11-20.

TACAIDS (2004). Tanzania HIV/AIDS Indicator Survey, THIS. Dar Es Salaam. <http://tanzania.usaid.gov/documents/HIVAIDSIndicatorSurvey20032004.pdf>

TACAIDS. (2003). 'National Multisectoral Strategic Framework on HIV/AIDS 2003-2007.' from [www.tanzania.go.tz/pdf/tacaidsnmf/pdf](http://www.tanzania.go.tz/pdf/tacaidsnmf/pdf)

Thomas, Felicity, (2006). 'Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and carer well-being in the Caprivi Region, Namibia.' *Social Science and Medicine* forthcoming.

United Republic of Tanzania (2004). *National Monitoring and Evaluation Framework for Hiv/Aids*. Dar es Salaam, Prime Ministers Office.

Uys, L. R. (2002). 'The practice of community caregivers in a home based HIV/AIDS project in South Africa.' *Journal of Clinical Nursing* 11: 99-108.

Van den Borne, F. (2005) *Trying to Survive in Times of Poverty and AIDS. Women and Multiple Partner Sex in Malawi*. Amsterdam, Het Spinhuis.

Weeks, J., Peter Aggleton, Chris McKeivitt, Kay Parkinson and Austin Taylor-Laybourn, (1996). Community Responses to HIV and AIDS: The 'De-Gaying and

'Re-Gaying of Aids. *Sexual Cultures: Communities, Values, and Intimacy*. J. Weeks and J. Holland. New York, St. Martin's Press: 161-179.

World Food Programme (2002). 'Country Programme Activity Summary: Integrated Support to Food Insecure Households Affected by Hiv/Aids'.





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