Community-driven development: understanding the interlinkages between individuals, community-based workers and institutions.

CDD Working Paper Series

Working Paper No. 5

Case Study: Community-based HIV/AIDS prevention and care systems, Northern Tanzania

By
Jelke Boesten

June 2006

Community-driven development: understanding the interlinkages
between individuals, community-based workers and institutions.

The purpose of this research is to identify the potential and constraints of community-driven management and service delivery by tracking the evolution of participation, in selected projects as shaped by the interface between individuals, community workers and institutions.

Pro-poor community-driven development is both enabled and constrained by individual identities, the actions of community workers and the workings of institutions. The positive aspects can be enhanced through a greater understanding of individual motivations, institutional processes and improved monitoring techniques. However, the limitations of such models must also be recognised.

This research has three objectives: (1) to understand individual participation in collective action; (2) to understand the contribution of community-workers to participatory processes; and (3) to understand the possibilities of 'getting institutions right' for pro-poor development.

The research analyses case studies of community-driven development activity in relation to water and HIV/AIDS in Tanzania and South Africa.

This document is an output from a project funded by the UK Department for International Development (DFID) for the benefit of developing countries. The views and opinions expressed are not necessarily those of DFID.

Research Partners:

Jelke Boesten (j.boesten@bradford.ac.uk),
Frances Cleaver (f.d.cleaver@bradford.ac.uk)
Anna Toner (a.l.toner@bradford.ac.uk)
Bradford Centre for International Development (BCID), University of Bradford,
Bradford BD7 1DP UK +44 (0) 1274 235286

Lindi Mdhluli (lindi@aicdd.org)
African Institute for Community-Driven Development (AICDD), 16A President Steyn, Westdene, Bloemfontein, 9301, South Africa Tel:+27 (0) 51 430 0712 Fax:+27 (0) 51 430 8322

Bertha Koda (bokoda2001@yahoo.com)
Comfort Mfangavo
Institute of Development Studies, University of Dar-es-Salaam (UDSM), Tanzania

This Working Paper Series is dedicated to the memory of

Comfort Mfangavo

enthusiastic research partner in Dar es Salaam.

CDD Working Paper Series

Working Paper 5

**Case Study: Community-based HIV/AIDS prevention and care
systems, Northern Tanzania**

By

Jelke Boesten

June 2006

Table of Contents

Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ADP	Area Development Programme (World Vision)
ART	Anti-retroviral Treatment
CBO	Community Based Organisation
CBW	Community-Based Worker
FBO	Faith Based Organisation
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
NACP	National AIDS Control Programme (Tanzanian)
PHC	Primary Health Care
PLHA	People Living with HIV/AIDS
SAIPRO	NGO for Agricultural Promotion (Migule)
STI	Sexually Transmitted Infection
TACAIDS	Tanzania Commission for AIDS
TBA	Traditional Birth Attendant
VCT	Voluntary Counselling and Testing
VC	Village Council

Tables and graphs

Key Findings

Community-based workers and beneficiaries
- Personal motivations and interests, which are related to socio-political position in the local community, shape the relationships between CBW and beneficiary.

- Prejudice with regard to HIV-positive people is also present among CBWs and local leaders; likewise, this affects the relationship between CBW and beneficiary.

- The idea of HBC seems an empty shell if i) stigma prevails which prevents socio-psychological support, and ii) if there are no treatments or even basic medication available. In contrast, groups of PLHA are able to do HBC as they strongly empathise with the beneficiaries.

Institutions and CBWs
- The lack of resources seems strongly linked to the *idea* of community participation and cost-effectiveness as held by the funding bodies. All discussed CBWs had received a basic training with regard to HIV/AIDS prevention and care from one or another institution but were largely left to fend for themselves afterwards. The meaning of HBC was unclear in this setting

- The high turnover of supporting institutions reinforces this 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, and the lack of a local formulation of a coordinated HIV response, leave community-based organisations fight in an environment of contradictory messages. This lack of coordination and clarity in the AIDS response also makes competition over scarce resources more probable, and thus, feeds into further disintegration of local interventions.

- Creating an 'enabling environment' through improved coordination and regulation of funds, improved and targeted legislation and implementation (especially with regard to PLHA-rights, gender issues, and sexual violence), and the creation of social safety nets would increase the possibilities for a holistic community approach to HIV/AIDS. This in turn, suggests the necessity for a return of the state.

Introduction[1]

The Project

This case study looks at three community-based initiatives and community-driven interventions to improve care for people with HIV/AIDS and to prevent its transmission in Migule, Tanzania. These projects were initiated by political mandate, by a regional women's organisation, and by a local initiative. The study of these three initiatives in Migule focused on the functioning of community-based workers (CBWs), ie., elected, selected, appointed, or self-appointed volunteers who worked in their communities to improve their situation. The questions that guide this study can be condensed in three key questions: a) How is individual participation in collective activity shaped? b) What is the role of CBWs in such collective activity? And c) What is (or should be) the role of institutions in pro-poor development?

After explaining the methodology, we first look at the community in which the case study is based. As the concept 'community' is central to the idea of community-based development, its nature is not only important to analyse case by case, but its definition should constantly be questioned and scrutinised. As we will demonstrate below, with regard to the present case study, the economic, political, and cultural make up of the geographical community of Migule is central to the success or failure of its HIV policies. The community profile of Migule includes administrative, political, and economic characteristics, services and institutions available, particular local problems, a localised problem definition with regard to HIV/AIDS and existing constraints to HIV policy effectiveness, and a brief outline of existing prevention measures.

In successive sections, we deal with the three initiatives with regard to HIV in Migule: i) a government appointed village health worker (VHW) system, ii) a district-level women's organisation with grass roots representatives, and iii) a locally organised group of people living with HIV (PLHA). These three examples of community-based interventions will be examined separately according to a range of themes: institutional make up, role in the community, tasks and reach, accountability, training, motivation,

---

[1] This paper has benefited from research group collaboration, especially with Anna Toner and Frances Cleaver. The study could not have been carried out without the dedication of Mariam Kinabo and Reuben Marissa, who worked on this project as Research Assistants in Migule and surroundings.

and conflicts and constraints to effectiveness. A fifth section examines the opinions of participants in the research.

In a concluding section, we will compare the three initiatives and frame them in the four thematic areas identified as problematic by comparing existing studies of community-based worker systems (Working Paper 1). The four concepts to examine are autonomy, responsibility, accountability, and professionalisation of community-based workers and the organisations they form part of. In addition, emerging themes that were not set out as objectives at the start of this research, such as what home-based care means, will be examined, and the central question of this research (how the interlinkages between CBWs, participants, and institutions look like) will be addressed.

Methodology

The research is based on ethnographic work carried out by one international researcher and two local research assistants. The research methodology was designed by the principal research team at the Bradford Centre for International Development and adapted according to local circumstances and thematic particularities by the international researcher involved. This main researcher has worked on the fieldwork for one year. In this year, four fieldwork periods of in average three weeks were undertaken. In the periods between fieldwork trips, there was continuous contact with, and guidance of, the two research assistants stationed permanently in Migule.

The research assistants received short trainings about doing research, data collection, methodology, and the ethics of research. The assistants' knowledge of the area and the ease with which they established new networks and strengthened existing ones was very valuable to the research. Their open mind and their interest in knowing the problems and concerns of the volunteers and their beneficiaries, the HIV-positive, the orphans, and their family members, have greatly contributed to this research.

The methods used are of an ethnographic nature: open and semi-structured interviews provides for the bulk of data, but group discussions, informal interviews and conversations, participant observation, and diary writing and photo-diaries were

equally important. Minute books and other relevant documentation were also studied. We interviewed HIV-positive persons in Migule and in surrounding communities, randomly chosen community members, representatives of age groups, of local institutions, doctors and nurses, and, of course, community workers (see the attached methodology section for further specification).[2] This method of examining CDD service delivery does not provide for hard data regarding improvements made in particular communities. However, it does provide timely information about mechanisms of inclusion and exclusion, about informal and formal institutions, and about attitudes and behaviours that might enhance or obstruct particular interventions.

---

[2] Names of towns, villages and individuals have been changed. Complying to the request of interviewed people living with HIV/AIDS, including members of Kikume, they appear with their real names. For the sake of anonymity of the town, however, 'Kikume' is a pseudonym.

I. The Community

In 2005, the town of Migule had an estimated population of 3000 families. Catering for a highly mobile population, however, some 19,534 (census 2002) to 21,000 (current estimates) people in the larger administrative entity of Migule-ward, including several nearby agricultural villages, depend on its public services.[3] Migule-ward pertains to an unnamed District (with a total population of 212,325 (census 2002)) in a Northern region (Tanzania being administratively divided into villages, wards, districts, and regions).

These communities are post-colonial. Farmers who were looking for better lands and more space for animals established them in the 1960s. The villagization policy of Nyerere (1973-1978) formalised and accelerated this process. Today, population pressure, changing hopes and values (and a good road connecting major cities and bordering countries), as well as environmental degradation, encourages people to move to road side towns and villages rather than agricultural settlements. Farmers in this area produce maize and black beans as staple food, buy and sell cattle from the Maasai, and grow some fruits and vegetables in the mountains, both for sale and personal consumption. The poorest -farmers with no land, or no access to water- might barter charcoal and building stones.

The relative short history of these communities means that their people are not homogeneous, although the majority are from the Pare tribe, coming from different communities in the Pare Mountains, immediately east of the main road. The area west of the main road is Maasai land. The common language –as everywhere in Tanzania- is Swahili, but most inhabitants also speak their own ethnic language. Few people speak English, indicating that few people have completed secondary education. As we will see below, Migule's reputation as a dynamic transit and trading town has led to illegal commercial activities. This has fed into the rise of Migule as a hedonistic stop for truckers, traders and other passers-by.

---

[3] The census 2002: http://www.tanzania.go.tz/census/census/districts/

Services in Migule

Migule is governed by a Village Council (VC) which consists of twenty-five members, sixteen male and nine female. The VC is responsible for local governance, but Migule also has a Ward Committee, in which representatives of greater Migule come together. A small elite of educated people govern the ward's main institutions. One person in particular holds several key posts in the ward committee, the dispensaries, the education committees, and several community-based organisations.

Migule has a public and a private dispensary. Both contribute substantially to the health care of the population, but can hardly manage the increasing population, the high HIV/AIDS prevalence, and resulting health problems. The public dispensary is directed by a medical assistant, doctor Kiringu, who is assisted by eight trained nurses. The dispensary deals with maternal health care, including family planning, and diseases such as malaria, pneumonia, respiratory problems, skin infections, and Sexually Transmittable Infections (STIs). People with TB are referred to the District hospital and treated for free. The expert on STIs is doctor Mwinyi, a physician who has his own private consultancy and occupies several key positions in Migule's institutions. As indicated above, in addition to the men and women of Migule town people from the surrounding rural settlements (including Maasai from the plains) attend the dispensaries.

In the field of *education*, Migule has seven primary schools, a primary school for children with down-syndrome and three secondary schools. Despite the occasional help of regional NGOs, the existing schools cannot cope with the number of students: they suffer from a systematic lack of teachers and resources.

Social order in Migule is maintained by the police and a system of customary law. Migule has a police station staffed by seven officers. The police's main occupation concerns traffic control. Taking into account the daily amount of national and international truckers stopping in Migule, it is plausible that the daily traffic controls

include some sort of taxation –albeit not officially.[4] The police only deal with those civil disputes that cannot be handled by institutions such as committees of elders in each neighbourhood, or subvillage ten-cell leaders. Appointed young men serve as security guards, known as militias, who intervene in violent disputes, catch thieves, and punish those community-members who do not fulfil their duties in the communal labour system. In sum, justice is largely in the hands of village elders and militias, i.e., on a community-owned system of social control and punishment.

This *community control* is also expressed in the compulsory participation in communal labour. Communal labour is imposed by the village council to contribute to the building of extensions on schools, dispensaries, and water and irrigation systems. People may contribute labour or a fee. This generates a sharp and visible division between richer and poorer people, although none of the interviewed community-members saw the system as unfair or undesirable. This idea of compulsory 'voluntary' participation in community development projects is rooted in the self-help socialism of Julius Nyerere and often clashes with the notions of 'participation' and 'voluntarism' as understood by international development workers (Marsland 2006). As will become clear throughout this paper, expectations of what community participation entails and how it should be shaped is fundamentally different in the development literature and practice as compared to local practices and expectations (Green 2006).

In the *religious sphere*, Migule is a mixed community in which Muslims, Catholics and Protestants live peacefully and respectfully together. All Churches in Migule have conservative views on sexual mores and encourage people to abstain from sex outside marriage and to be faithful to their partners. The Churches have community organisations such as committees of Church elders and women's groups. Although these organisations might support ill or otherwise deprived people economically and emotionally, they do not explicitly support PLHA. HIV-positive Church members are in general not open about their status in the Church community. There are no funeral societies or otherwise formalised social security networks.

---

[4] Ellis and Freeman (2003) noted that Tanzanians pay a wide array of legal and less legal taxes and fees, and that local police officers might be inclined to levy taxes on road blocks. Considering the nature of the trade in Migule and the visible nightly traffic controls, this seems very plausible in our case study.

Trading food, alcohol and sex

The main road from Dar Es Salaam up to Kenya and Uganda, which passes through Migule, has created new possibilities for trade. National and international truckers and traders choose Migule, strategically located between the cities Arusha and Dar Es Salaam, and between Pare Mountains and Maasai plains, as a stopover. In the Pare Mountains, *mirungi*, a stimulant drug elsewhere called *khat,* is cultivated for sale in the lower plains. Surely this has contributed to Migule's popularity as a stop-over. As such, the town's road-side businesses of food, drink and prostitution are thriving. This has fed into the high levels of migration from rural agricultural mountain areas to the more urbanised and economically promising area of Migule. However, the economy offers few alternatives besides serving lorry drivers and traders. Many girls and young women seek out Migule to make a living for themselves and their families. Interviews showed that not only young women from the mountains, but women from Dar es Salaam, Mwanza, Arusha or the regional capital regions come to Migule for business. As one sex-worker claimed: 'we (sex workers) put Migule on the map'.

Despite the presence of a thriving sex industry there is no clear, unified town or district policy to curb the AIDS epidemic associated with commercial sex work. Migule presents us with a social environment full of contradictions: whereas everyone knows that sex work is the economic backbone of the town, and few attempts are made to banish or even control the sex trade, a moral taboo is placed on adultery, on having multiple sexual partners, and thus, on openly using and/or promoting condoms. As such, the centrality of commercial sex as a survival strategy, the high prevalence and opportunity for doing so in a poor trading town with weak communal roots such as Migule, and the correlation between commercial sex and STIs, including HIV, make Migule an ideal place to study the contradictions in the fight against HIV/AIDS.

Transactable sex and unsafe practices

The situation of economic deprivation of many rural migrants and urban poor in African towns is likely to contribute to women engaging in sex work as well as to the

multiple forms in which sex is exchanged for goods or cash. Sex, then, is a 'transactable' asset for women and is often not only bound up with intimacy, but also with economic strategy (Setel 1999: 120, Bujra and Baileys 2000: 7, citing Akeroyd 1997; Van den Borne 2005).[5] Setel, looking at the regional capital-town, identified some ten different forms of sexual relationships in which the exchange of goods, food or money is central to the relationship (Setel 1999: 104-108).[6] The most common terms referring to explicit commercial sex –as contrasted to arrangements in which men occasionally but repeatedly provide for women in informal sexual relationships- are *malaya* for prostitutes, and *kuuza baa/kufanya kwa gesti* for bar girl/guest house worker. As such, bar work is strongly associated with sex work (Gysels, Pool, and Nnalusiba 2002: 186). In Migule, prostitution is concentrated in bars and guesthouses. The town has around ten (visible) guesthouses, in which on average two to three girls work per night or day. We have not been able to verify how many less visible arrangements exist.

Whereas *malaya* and *kuuza baa*-work are explicit forms of commercial sex in a time when and in a region where HIV is epidemic, there is no public 'collective strategy' to improve the safety of the profession. Bars and guesthouses are supplied with condoms (by CBOs) and one can buy them in shops and bars chaeaply ($ 0.10 for three). Nevertheless, interviews showed that it was not always possible for women to negotiate condom use. Evidence from an Ugandan trading town similar to our case study in Tanzania, suggests that the use of condoms is largely determined by the different meanings given to different sexual relations. If a man returns several times to the same woman, he becomes a 'regular' and it becomes more difficult to demand the use of a condom. In addition, many women have 'regular boyfriends', or partners who support them materially in exchange for sexual and domestic services. According to this study, the more 'regular' a partner is, the less likely it is that a condom will be used (Gysels, Pool, and Nnalusiba 2002: 183). Women in Migule confirmed this image. One informant said she did not use any condoms with her clients because she mainly lived off a network of regular clients who she had known for years. Only with 'new' clients could she (temporarily) use condoms. Her sexual partners only

---

[5] Linking poverty and prostitution and calling for poverty reduction strategies in line with HIV prevention in Ghana and Thailand: Worlamyo Aheto, Prosper Gbesemete, (2005).
[6] Setel's categorisations are also reflected in the work of Bujra on AIDS and sexuality in Tanzania, as well as the work of Frances Vavrus.

demanded condom use in the two days after her menstruation, believing that the remaining blood in her body increased the risk of transmission. During menstruation, men did not want to have sex with her at all.[7]

Some girls maintained that they used condoms, always and with everyone. Although this sounds possible and encouraging, it is unlikely that such a safe sex politics is universal. As we saw above, it is not common to use condoms with regular or long term manfriends. All our informants said to be terrified to go testing for HIV, as they were indeed conscious of the dangers of unsafe sex -and of the consequences of being tested positive.

However, there are many other forms of unsafe (i.e., without knowing some ones health status, not using condoms, and/or with multiple partners) sexual encounters. People refer to very young girls being tempted (*tamaa*, desire) to accept very little – food, drinks- in exchange for sexual encounters with older men. A sex education campaign developed by the anti-AIDS organisation Wanawake confirmed this idea: posters explicitly drew attention to young women who have sex in exchange for 'sodas and chips'. In the framework developed by Setel with regard to sexual arrangements, this type of relationship is usually referred to as *awara*, 'sugar daddy' (1999: 105; also: Haram 2005, Silberschmidt, M. and Rasch V. 2001). The level of coercion involved in such relationships is unclear.

The accusation of older generations that the young of today are 'loose' is, of course, largely the product of any generation gap in any society and the accompanying shifting moral norms, or 'cultural dislocation' (Setel 1999).[8] The idea that youngsters act upon their desire for modern goods using their sexuality encapsulates a rejection of such shifting norms. Young people engage in love affairs, casual sexual relations such as one-night stands or short relationships, which are referred to as *starehe*. Conversations with young men and women (between 18 and 21) indicate that among

---

[7] Interview with E., Survival bar, 15-06-05. Mrs Msinga's interviews with neighbours confirm the lack of condom use among sex workers (see diary 23/06/05)

[8] For example, representatives of community-projects funded under the umbrella of the Rapid Funding Envelop (see WP 2, Mfangavo 2006) at a TACAIDS conference in Dar es Salaam in January 2005, referred repeatedly to the dangers of dancing in rural villages. This would create the possibility for young people to experiment with sex in the bushes and seen as a major moral transgression causing high HIV prevalence.

peers casual sex is not disapproved of, rather, is sought out, especially during the weekends, and that condom use is not consistent. The use and safety of condoms was disputed, due to an often contradictory absorption of information (the moralising Churches, media increasingly open towards issues related to sexuality, fearful parents, and biomedical approaches of international representatives/NGOs).[9]

The final unsafe sexual encounter between men and women which is relevant to mention because of its widespread prevalence is a form of informal polygamy called *nyumba ndogo*, or 'little house' (Setel 1999: 104). This refers to men housing and maintaining a lover, often with children, outside their marriages. In *nyuamba ndogo*, the multiple sexual encounters are obvious, as fidelity is not expected from the man, and although perhaps expected, in fact not always lived up to by women (Setel 1999, Haram 2005). However, as condoms are usually only considered to be used in one-off transactions, and not in a relationship, this form of sexual encounter is likely to be vulnerable to STD and HIV infection. Several women we spoke with in Migule found themselves in such a situation.[10]

HIV/AIDS in Migule

The nature of the town's commercial activities and unsafe sexual practices has made it a breeding ground for STIs, including HIV. Official statistics show that 5.5 per cent of pregnant women who attend the government dispensary in Migule are HIV-positive. At the District hospital, eight per cent of blood donors tested HIV positive. In the same hospital, 15 per cent of people who went for a voluntary test between January and May 2005, were tested positive. Of those persons admitted for other illnesses, almost half (46 %) was tested HIV positive.[11] The newly appointed expert nurse in Voluntary Counselling and testing (VCT) in Migule town, estimated that 20 per cent of persons who came for VCT were tested positive. The range of difference between these percentages –from 5.5 to 46- makes it difficult to map the problem. Considering the difficulty of testing representative populations, official statistics do not necessarily reflect the actual extent of infection. According to both the public and private medical

---

[9] Group discussions in Mmwini 16/06/05.

[10] For example: Interview with A. M., 24-03-05.

[11] Mr Msinga Diary: hospital numbers Jan-May 2005, 5-7-05. 46 % tested HIV positive among hospitalised people is, of course, not the same as 46 % of non-hospitalised persons.

practitioners in Migule town, few people test for HIV, while many are suspected to die of it. Whereas antenatal tests are often used as estimates of HIV among the general population, such tests are not necessarily representative. First, not all women make use of the medical services.[12] Second, antenatal tests provide a selection bias and exclude large parts of the general population, and third, HIV-positive women are biologically less likely to become pregnant. A walk through one neighbourhood with CBWs of the CBO Kikume, suggested an infection rate of one in three families. The main primary school, Mbuyuni, counted more than ten per cent orphans among pupils. However, interviews with families suggested that there were many more orphans who did not attend school because of a lack of funds for school uniforms and materials. According to the CBO Kikume, in 2003, Migule has 574 orphans.

A majority of interviewed PLHA had other family-members who were also infected. Not only sexual partners were HIV-positive or had already died, but children, brothers and sisters and, in two cases, parents, were also infected. According to the members of the studied CBOs, Kikume and Wanawake, people who take care of their sick relatives are easily infected because of a lack of knowledge about hygiene, protection against transmission, and, if they do know, because of a lack in materials such as plastic gloves -although no evidence suggests that this is a real danger and care-givers infection rates do not figure in statistics and estimates.

Another form of HIV transmission is mother-to-child: Women can transmit HIV to their newborns during delivery and breastfeeding, as delivery is not always done under ideal hygienic circumstances, because the status of the mother is only known after delivery, or because mothers breastfeed their children despite their status (it is estimated that less than five per cent of infections are through mother to child transmission). Today, pregnant women who are tested HIV-positive receive anti-retroviral treatment (ART) in the District hospital for six months after the birth of the baby (the period of breast feeding). Although there is a small chance of transmission through blood, this is negligible according to the governmental body that deals with AIDS in Tanzania, TACAIDS. Other transmission routes such as sharing needles in

---

[12] We personally met at least one woman who avoided the medical services to get an illegal abortion somewhere else. One of the nurses also claimed that students had self-induced abortions, meaning that much sexual activity goes unnoticed by the official statistic makers. Also, we do not know how many women attend the dispensary, and how many prefer the many TBAs in working in the area.

drug use, or 'traditional skin practices', are also rare, but they do exist.[13] This leads us to confirm the known: the bulk of HIV transmission in Tanzania is caused by unprotected heterosexual contacts.

As testing for HIV was relatively recent, testing facilities were only scantily available, and most people only tested when AIDS had passed the doorstep, people easily transmit the virus to their sexual partner(s). This reluctance for knowing one's health status was related to the prevalent moral judgement associated with HIV. Patterns of blame and stigma attached to those infected prevented many people from being open about their status. Being open about HIV status could also frustrate peoples' livelihoods strategies. For women, who in part depend on men for economic support, information and patronage (Van den Borne 2005: chapt 4), being tested HIV-positive could mean an end to existing relationships and an impediment to finding new (sexual) partners who could help economically. Other income generating activities such as selling prepared food also becomes increasingly difficult when tested HIV-positive. For men, testing HIV-positive could also mean an end to multiple sexual relationships. At the same time, the stigma attached to HIV/AIDS makes finding an income increasingly difficult, as few employers like to contract men with HIV.[14] Prevailing masculine identities, in which virility and fertility occupy central places, receive a severe blow. Bujra 2002; Van den Borne 2005; Nnko et. al. 2004). Women's femininity might receive a similar blow because of the 'promiscuity' stigma attached to HIV/AIDS, which would mean an open sign of having transgressed moral codes. As a result, some people prefer to keep quiet and not voice their suspicion of a possible HIV infection. This can be altered, as we will discuss below, by offering concrete support: the availability of food support and medicine for PLHA were major incentives for people to go for tests and to 'come out' and be open.

Prevention Strategies
Considering the fact that HIV is in the majority of cases transmitted through sexual relations, prevention strategies should be focussed on changing sexual behaviour

---

[13] TACAIDS 2003: 14. An incident in Migule showed how a witchdoctor used human and animal blood for his ceremonies. Measures to prevent infection in such blood fuelled ceremonies are scarce. In: diaries June 2005.

[14] The issue of HIV/AIDS and the labour market/workplace is increasingly highlighted in research and activism, See Bertha Koda, June 2005.

through the promotion of safe sex. The definition of safe sex, however, is disputable. One of the major sources of information regarding HIV in rural areas, including Migule, is the churches, and these promoted their own moral interpretations of behaviour change. Several churches legitimised people's reluctance to use condoms by maintaining that they are bad –morally or actually, i.e., that they would not be safe- and by telling people they should not use them. They preached abstinence in a town that is visibly not abstaining. The different religious groups' ambivalent positions in this abject epidemic also led to confusion among the population as there was no straightforward message of how to stop the disease.[15]

At the same time, the churches do get involved in AIDS prevention and care. Most congregations in Migule had some sort of programme in place, being that in theory or in practice. These programmes included awareness-raising, counselling, and HBC (SDA Church), HBC training and poverty reduction through micro-credit for women (Catholic women's group, Wawata), and financial support to the neediest and to those who need hospital care (Lutherans). Interviews with Muslim leaders indicated their commitment to AIDS awareness in their communities, although this did change their views on polygamy or the use of condoms.[16] In addition, many CBWs were active in FBOs as well. However, despite this commitment to HIV/AIDS prevention and care, the rejection of condoms and the strong moral judgement against sexual activities outside monogamous marriages parallel to the thriving sex industry contributed to the confusion among community members of what safe sex is (especially among youth), and to the stigma that rests on people living with HIV/AIDS.

Other sources of information about HIV are the school, community workers, and healthcare workers. Nevertheless, prevention education was scattered and uncoordinated: a seminar here and there, in large part offered by organisations for development such as World Vision (international) and SAIPRO (a district level NGO for agriculture). There was no consistent sex education in the school curricula,

---

[15] A comparative study to prevention strategies in rural Ghana and Thailand observed similar confusion. Just as observed regarding Migule, in Ghana the churches were a source of information on HIV for the population, however, the various religious groupings transmit different views about HIV and condom use. The study emphasises the need for harmonising the teachings on HIV/AIDS in the communities to achieve a common purpose. Worlamyo Aheto and Prosper Gbesemete, (2005).

[16] One imam argued that polygamy within marriage would prevent men from having sex elsewhere, thus preventing the spread of HIV. Interview Abdalah Hamisi, Mmwini, 15-04-5.

although the national government proposed to start sex education at primary school level. The head teacher of one of the largest primary schools in the ward claimed that her school taught a special subject on HIV in Standard Five to Seven. As she is a member of the women's organisation against AIDS, Wanawake, it would be consistent if she and her school were actively teaching HIV prevention strategies to the children. The regularity of this course could, however, not be verified, nor could the contents.

A behaviour survey among Tanzanian youth carried out in 2002 indicated that the majority (more than fifty per cent) of youth were aware of prevention strategies and the value of condoms in prevention of HIV transmission. Nevertheless, only a small minority used condoms in their first sexual encounter. NGOs realise that peer education would be more effective than HIV courses in the formal education system. In Migule ward, young people were being trained by World Vision to perform such roles. The organisation aimed to finance a youth centre and train and supervise peer educators. Conversations with young people suggested that such informal schemes could provide for a better learning environment than formal structures in which sexual education is delivered.

As indicated above, a problem in the prevention strategies that were developed was the lack of clarity among community workers about what safe sex is and what strategies could be employed to avoid HIV transmission. For example, a common belief seems to be that physical efforts distract from sexual desire (Vavrus 2003: 103; Setel 1999:163). Several interviewed health care professionals claimed that hard work distracts and keeps people from having sex outside marriage. They also maintained that there are fewer patients with STIs during the rainy season than during the dry season as people work the fields during the wet season and do not have the time or the energy for sexual escapades. In addition, HIV-positive women who had households to manage were discouraged from engaging in sexual relations following a similar line of argument: They were told that the energy that sex uses up equal energy as if running nine kilometres. As ill mothers with children to care for before they die, women were told that they could not afford to waste such energy. Several women

claimed that this advice was given to them at the district hospital.[17] Although it might seem a harmless advice at first hearing, it is an unfair and prejudiced way of keeping HIV-positive women from seeking sexual intercourse without confronting issues of power and protection. In addition, it adds a moral layer to HIV prevention, which does not necessarily help to reduce stigma, or help people to effectively seek protection.

Another unclear point among community workers, as observed at a workshop for CBWs, is how HIV can be transmitted.[18] A highly esteemed and respected doctor present told the attending CBWs that saliva contains HIV. As a result, confusion emerged about which sexual activities should be seen as 'risky'. Whereas the involved doctor was not confident on this issue, he chose to tell the participants that safe sex is always 'without romance': you use a condom and 'forget about the rest' as that could be dangerous. Whereas another health care professional intervened to tell the participants that one needs litres of saliva to pose a danger, this was not convincingly conveyed as a reason not to fear kissing. The message also generated a contradictory message regarding the sharing of food and plates and cups, an almost unavoidable practice in the largely poverty stricken households of Migule. The lack of clarity regarding the transmissibility of the virus through sharing kitchen utensils also prejudices HIV-positive street vendors.[19] In sum, unclear and often contradictory messages about HIV transmission among those who are seen as authorities on the theme (community-workers, doctors, Church leaders, school teachers) do not contribute to prevention efforts.

Community-based health care

'Despite the appearance of a strong public healthcare infrastructure, in reality, Tanzania suffers from chronic shortage of supplies, underpaid staff, lack of adequate training for clinical staff and voluntary health workers, and limited accountability for the performance of services at each level.' (Hanson 2000)

---

[17] Eg Interview A. F., Migule, 24-03-05
[18] Wanawake Seminar 29-04-05, Migule. Often, bio-medical knowledge about AIDS transmission and other, more transcendental explanations exist side-by-side. God's Will, chance, accident, and witchcraft are all possible explanations for contracting AIDS. See: Mshana et al (2006).
[19] Other research considered such attitudes as typical stigmatization of PLHA: ICRW (2002)

The health care system in Migule was not prepared for the problems the town faced. In 2005, the Migule government dispensary was not equipped with HIV-testing facilities, although a nurse specialised in midwifery was recently trained as a VCT counsellor. The attending doctor was a medical assistant trained at a medical college and had limited qualifications. As a response to increasing concerns over STIs and HIV transmission, recently efforts were made to improve the facilities in Migule. The EU provided training in STI counselling, village health workers were appointed to all subvillages, beds were also provided, and facilities to take blood installed. The blood samples still have to Laboratory facilities to test the blood are the district hospital. In how far these improvements will be effective was not clear at the closure of this research.

The attending health care personnel claimed that they did not do much VCT counselling because few people wanted to test. The apparent lack of trust in the health care services did not contribute to that situation. According to various informants, people shun the government dispensary because of a lack of privacy. People felt uncomfortable to attend testing and counselling services in a public place where other villagers come with non-HIV related problems. They did not trust the health care personnel to be discrete about their business either. People who received their testing results at the dispensary were, according to informants, left alone, without any follow-up counselling.[20] However, the midwife who received additional VCT training had a well-established reputation among the population and had good contacts with the different CBOs as well. She started her work in Migule as official HIV councillor in June 2005. This person observed that whereas in the long term the presence of VCT in Migule should improve the care for HIV-positive people and the willingness of people to go testing, people were still reluctant to go for testing, wait for the results from the District hospital (where the laboratory is located), and come back to the Migule dispensary to hear their results. The VCT nurse was often left with positive tests but nobody to inform this to.[21] At the same time, because transport costs money and the health care personnel has little time to bring blood samples to the District hospital, picking up the results was difficult and often delayed.

---

[20] Conversation with Msinga and Kipingu, Migule, 10-06-05;
[21] Interview J. G., 4-7-05

Improving VCT services was not only difficult because of issues of trust and confidence. The question should also be raised what to do with people when tested positive. Up until now, no anti retroviral treatments (ART) were available to the population of Migule. Several people may enter ART programmes in the district hospital, but for the majority this is unattainable as few free treatments are available. The medical personnel at the Migule dispensaries admitted that they saw many AIDS related diseases among people who had not been tested. The personnel could treat people for the opportunistic diseases, but not for HIV because there were no medicines available and because people did not want to go for tests. Both interviewed professionals indicated that they usually did not ask or even advise their patients to go for an HIV test, as this was seen as imposing tests on patients. One doctor claimed that advising patients to undertake a test might result in a violent response and would in general not lead to any improvements. There is clear reluctance on the side of the doctors to get mixed up in advising people to go for a test. Such an approach implies that without the availability of ART, the positive effective of testing is minimal from a medical health perspective. Such a train of thought suggests that there was no feeling of responsibility towards the rest of the community being in danger of infection either.

Formally, the dispensary had a home-based care programme. The attending medical assistant and several nurses received European Union-funded training from the government.[22] The result can be read on a large piece of wall paper in the dispensary, which shows the aims and objectives framework of the programme. However, it does not seem to function very well. The doctor claimed that they do visit ill people at home, but, when asked, he said that they had had four chronically ill patients last month who were dead by now. At the same time, the doctor complained that he had no time to visit patients after his normal working hours and he had only a bicycle for transport, which is indeed hardly useful on dirt roads at night. The nurses did sometimes perform home visits, but they did not do so in a structured way. Thus, a HBC system that depends on the voluntary work of low-paid but hardworking professionals did not seem viable. Community members' voluntary work might provide for this gap in health care services.

---

[22] Interview with doctor K. 31-04-05

II. Government-initiative: Village Health Workers

In 2004, as part of the multi-sectoral framework (Working Paper 2, see also page 38), a Village Health Committee (VHC) was established.[23] This committee consisted, in principle, of all relevant community representatives including physicians, a ward counsellor, two youth (one woman, one man), PLHA, FBO and CBO representatives, and any relevant private sector representatives. Although the committee officially existed in our study area, most people, including the supposed members, were not aware of it. Decisions regarding health care were still made by the established health care authorities, in this case, the medical assistant of the state dispensary and the physician of the private dispensary, doctor Mwinyi, who is also the District Health officer and the Chair of the Ward Council. The newly established VHC agreed to the appointment of Village Health Workers, trained by World Vision, in all sub-villages. In this section, we will examine the functioning of these government-appointed voluntary community-based workers.

Institutional Linkages

Village health workers (VHW) have been active in Migule since the early 1980s. As in many places throughout the world, community-based health care workers were an important component of primary health care systems in order to improve access to services in rural and underserved areas in a cost-effective and culturally appropriate manner (Boesten 2005). International NGOs and faith based organisations trained community members to support the activities of the Primary Health Care services. 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).[24] The Catholic Church was also active from an early stage, while the trained health care workers often worked closely with local state services. Throughout the years, VHW received training and support from these different institutions.

---

[23] Confirmed in an interview with doctor K. 15-06-05

[24] Also: interview with Neatness Gideon, Director Marie Stopes district office. These trained community-workers, or peer educators as they are also referred to, often drop out, loose interest.

There is a core group of people who volunteer for such community-based work, who work with the different institutions, and who were also appointed under the 2004 government scheme of VHWs. These persons were generally perceived as community leaders and as being capable and trustworthy by their local community. The VHWs reported to the PHC secretary, a health care professional at ward level. For medical supplies and technical advice, the VHW relied on the government dispensary and its medical assistant. In practice, this did not materialise as the dispensary lacked sufficient materials such as gloves or adequate medicines. The little knowledge the responsible dispensary doctor had of the VHW programme indicated that contact was not consistent. The head nurse at the dispensary indicated that the VHW could not contribute to actual health care, but did provide information about sick people in their neighbourhood.

Training: feelings of insufficiency

For the VHW programme set up in 2004, the appointed CBWs received training from World Vision, the main international actor with local presence area at the time. Nevertheless, in interviews held in 2005, all VHWs indicated that they lacked the knowledge to do their jobs well. Nevertheless, as observed above, most VHWs received training from different organisations. The majority of interviewed VHW have been already active for different programmes since ten or twenty years. During this time, they received training from Marie Stopes, World Vision, the district government, and Caritas. Why did the VHW still indicate that they have not received enough training? To answer this question we need to look at several factors which include different interpretations of power and knowledge, of care and health, and of participation.

First, the fact that training came from different organisations, with different perceptions of health care and community participation, strategies, and priorities, could mean that the training received from different institutions did not complement each other. The incompatibilities could have created confusion in some aspects while repeating existing knowledge in other aspects. The lack of continuity in supervising agents and institutions cannot have contributed to the efficiency of the volunteers

either. The different expectations embedded in the different programmes further blurred the coherence of training acquired over time.

Second, perhaps the ideological, normative notions embedded in capacity building interventions impede the effectiveness of offered training. 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 targeted workers, and b) the existing power structures and communication lines (Green 2006: 5). Offered training and local practices may just fail to meet in the middle.

Related to this discordance about necessary skills and good governance, it could be that the teachings offered are not specific enough, not sufficiently relevant to the local situation. Local circumstances, such as available foodstuffs, transport problems and the situation of medical supplies and local supervision, should be taken far more into account in training offered.[25] In addition, the social relationship between a voluntary community worker and a HIV-positive or AIDS patient may not be so straightforward either. Idealised notions of what community solidarity is sometimes obscure local prejudice and conflict.

Third, the supervising institutions expect and rely upon the capacity of selected VHW to transmit knowledge among their peers. This 'Training of Trainers' (ToT) does not seem to have the expected results. The trained trainers are expected to transmit knowledge for which they went to a well-financed course that lasted perhaps five days. However, when they go back to their communities, they are expected to teach their fellow volunteers the same knowledge. In general, this leads to a five-minute briefing. These volunteers lack the time, money, and capacity to repeat such courses in a comprehensive way.

While it may be mistaken to rely on volunteers' ability to teach their peers, at the same time there seems to be a waste of knowledge because of a lack of discussion. Although the VHW are supposed to come together every three months to discuss their

---

[25] This problem was also observed by a representative of CARE, an international NGO with high-profile HBC programmes in different districts. Interview D.R., Dar es Salaam, 21-10-05

work, genuine discussion in which knowledge is exchanged, questions asked and mutual support provided does not seem to be part of these meetings. A culture of dependency and hierarchy (Green 2006) obstructs a constructive debate about the problems faced. Together with the apparent lack of actual activity among the VHW, the meetings have become obsolete. An attempt to encourage discussion among volunteers may help to make better use of the existing knowledge among VHWs.

Fourth, complaining about the lack of formal training also has to be placed in the perspective of the social relation between complainant and listener. The VHW complained about training to a research team from abroad, perhaps assuming that by doing so, access to the resources held by this research team could be acquired. Although there are many more issues at play than opportunistic lobbying, this element should, of course, also be taken into account.

Motivation: natural leadership, responsibility, and incentives

The existing VHWs were appointed in 2004 as part of the new national health care strategy. The community was asked to propose two candidates for participation per sub-village. The selected candidates were active community members, perceived as leaders in their sub-villages. This includes people who used to be active in FBOs, CBOs, but especially those who were village elders, ten cell leaders, and long-term Village Council members. The VHWs are political appointees, visible, for example, in their active participation in the CCM electoral campaign in 2005. In principle, the VHWs see their voluntary work as part of their commitment to the community, as taking part in the Village Council would be. As Rebecca Marsland observed (2006), participation in community development activities as organised by local government is interpreted as a duty.[26] In addition, Green (2006) observes that such forms of participation suggests the possibility of coming closer to government, and thus, closer to the resources it has to distribute.

Nevertheless, this time a small monthly compensation of 15,000 Tsh (appr. US$ 15) was promised to the appointed VHWs and thus the expectations in this particular

---

[26] Marsland (2006) observed different interpretations of 'participation': a locally understood form of community-participation rooted in the socialist self-help state of Nyerere, and the international development interpretation of participation of empowerment and increasing democratic decision making.

scheme are different. The promised fee was, however, only paid once. The village council argued that with a chronic lack of income there simply is no money to pay. The council's chairman indicated that he thought that being a VHW was part of the same community responsibility as being a counsellor, i.e., a voluntary job (albeit with compulsory connotations). But several VHW indicated that they could not do their work because of the lack of compensation. Others said that their work might be done better if they had 15.000 a month to spend on support for the chronically ill.

Incentives, especially when promised, are important to those who are doing the job. Although the work of a VHW seems to be part of the responsibility of community leaders, and is thus accepted as a voluntary and honourable task, increasingly monetary compensation is expected. This has to do with the raised expectations after several institutions granted a stipend, but also with actual necessity to carry out the tasks. Some institutions gave bicycles to VHW in order for them to make home visits and to come to meetings with other VHW. However, according to the VHWs, maintenance of those bicycles is difficult. Similarly, most VHW see it as an important part of their job to provide families with small economic support such as a bag of sugar or some cooking oil. Such foodstuff items can help to establish a relationship of trust with often-suspicious families.[27] The VHW will pay such items out of their own pocket, but this creates, of course, a situation that is difficult to sustain, as the volunteers themselves are poor themselves (whereas this non-kin form of giving is also a statement of power).

The lack of financial means among all villagers, including village leaders, means that volunteers have to rely on their own resources. As a result, some community volunteers draw the conclusion that they have the right to appropriate parts of external funds destined for the project. This, in turn, generates conflict among the volunteers and the beneficiaries. Money, who receives it, why and how, is a consistent source of gossip and conflict in the village. As we will see in the cases below, transparency and accountability within the organisational groups does not seem to be commonplace and

---

[27] According to the different HBC carers, family members who take care of AIDS patients are often hostile to visitors as they might just come to 'look around' and make fun of them. The stigma attached to AIDS obstructs decent and effective care for patients, as the stigma is prevalent within families.

there is no general agreement on how to hold community-based service providers to account.

Tasks

One major aim of the 2004 community and district health care strategy was to improve hygiene and environmental care through the installation of toilets and appropriate waste management. The VHWs were supposed to identify families who did not have a toilet and urge them to built one. Similarly, they checked on neighbours waste management habits. The VHWs were held responsible for the achievement of the goals in their neighbourhoods. They would, therefore, check on families' progress on a weekly basis. If families did not comply with the new rules, the VHWs could call on the help of militias in order to force people to comply. Of course, the possibility of force gave the VHWs a different status than the self-sacrificing home-based carer image might suggest. This para-military back-up to VHWs tasks questions, as suggested above, the nature of 'participation' as understood by the development literature (Marsland 2006).

Formally -ie. as established by the government Multi-Sectoral Strategy-, VHWs were to deliver home based care (HBC) to fellow community members with HIV/AIDS and carry out preventive activities. The WHO defines HBC as 'the provision of health services by formal and informal caregivers in the home'. However, providing health services is beyond the capacity of the VHW for the above-discussed reasons (training, resources, hierarchy). The limited availability of medicines in Migule limits the possibilities for health service in general. As such, as elsewhere in resource poor settings, home-based care often turns out to be palliative care (Farmer 1999: xxi).

If HBC is, however, above all palliative care, we need to ask the question who should perform this task. Considering the fact that HIV/AIDS is a sensitive issue and care a very intimate one, the fieldwork in Migule raised questions regarding the appropriateness of appointed village health workers to deliver such services. Perhaps we need to ask who traditionally performs caring tasks and try to strengthen their capacity and access to support. In other words, should family members be trained instead of appointed voluntary workers (Olenja 1999)? If so, should there be specific

emphasis on female family members? Is lack of capacity and resources the problem, or is stigma at both family and community level a greater constraint to delivering care to AIDS patients? Should appointed VHWs be expected to deliver HBC in the first place? Are other community initiatives more successful, and if so, why? These questions will return in our case study conclusion.

Prevention, Religion and HIV/AIDS

As indicated above, several of the VHW were active in FBOs. It is important to ask if religious convictions influence the prevention message they promoted in their communities. The answer is yes and no; in general, in Migule it was accepted that one promotes one type of behaviour in the Church, and another outside. Although this is extremely contradictory, even interviewed religious leaders said that it is alright to say (and do) one thing in Church and another outside. In this manner, religious persons, including leaders, were able to promote condom use when they were not speaking 'as a Priest/Imam/Pastor'. For example, one VHW used to be an Imam, but claimed to promote the use of condoms as a VHW. He saw it as his task to promote state policy (condom use) in his VHW task, but at the same time, rejected condom promotion when performing his role of religious leader. Several informants have indicated that, despite the obvious contradiction, this is an accepted way of dealing with the issue of sexual practice and prevention messages. Unfortunately, such an approach is detrimental for the way that recipients of such double standards interpret the safety and legitimacy of condoms –and the moral judgement attached to using them.

III. Wanawake: Women against AIDS

The second community-based initiative in Migule that we will consider in this case study is a local branch of a regional women's organisation. The organisation deals with PLHA and orphans, and has as a specific goal to empower women. The main activities and tasks of the organisation are carried out by local volunteers.

Institutional arrangements

Wanawake was set up in 1990.[28] The main goals of the organisation are to empower women to deal with the HIV/AIDS epidemic in their communities as well as developing mechanisms for protection against AIDS; to help and support people living with HIV (PLHA), their families, and orphans left behind; to help restore dignity and self-respect among PLHA; and to develop mechanisms for prevention.

Wanawake is a women's organisation with the clear objective to work with and for women. Men may become members, they may participate (and they do) and benefit, but they cannot vote or occupy leadership positions within the organisational structure. The organisation is rooted in a women's ideology directed at both the care-giving roles of women (their voluntarism depends largely on that idea) and the necessity for empowerment of women as leaders, individuals and carers. Thus, a maternalist presentation is combined with more feminist goals.

Wanawake assists approximately 200,000 people in the region (of an estimated population of 1.4 million, according to Africaso), they can count on some 700 volunteers and more or less 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 regional offices directed by (paid) coordinators. The Directive Committee consists of five members of the regions, four of the head office, and two PLHA (a man and a woman).

---

[28] This reconstruction is based on interviews with the Orphans Programme Officer in the regional head office and the district coordinator.

Wanawake divided its tasks in four main departments: 1) Home-based care, 2) health and prevention education, 3) counselling and testing, and 4) orphan support. These different sections are financed by different donors, mainly international NGOs such as USAID, Oxfam Ireland, and the Rotary of Bergen and another 20 more different organisations, including a small contribution from the Tanzanian government AIDS programme, TACAIDS. In addition, Duke University delivers medicines, advice, and research, especially in the area of home-based care. Since 2003, the World Food Programme has offered foodstuffs to families affected by HIV/AIDS, which is channelled through the orphan programme and the HBC programme. This particular component of support has generated its own set of problems, which will be discussed in detail below.

On a local level, the Wanawake branches are expected to work with religious groups and Churches, with other NGOs and CBOs (in umbrella organisations for example), and with local hospitals and clinics. Wanawake appears to be a success because it is an indigenous organisation building on the idea of solidarity among people, women's traditional caring tasks, and community responsibility -community broadly understood as a socio-geographical area- which, depending on the strength of the organisation and the participation of community members in Wanawake-related activities, can include villages throughout the ward (as is the case of Migule ward). As observed above, Wanawake works with all kinds of organisations, including the government and foreign researchers, and adheres to the different (national, but especially international) ideological standpoints. This versatility and approachability make them popular with the donors and interesting as an institution. If these aims and objectives are met on a local level will be examined below.

Migule Ward: Women against AIDS

One of the 76 branches of Wanawake at grass roots level is located in Migule. This branch will be examined as an example of how the organisations' goals and objectives turn out at the grass roots, and, in particular, to look at how community members participate in local initiatives with regard to HIV/AIDS. Although Migule presents an example of how Wanawake operates at local level, we have observed that local performance can differ across the branches. Nevertheless, several of the possibilities

and constraints identified in this case study lend themselves for generalisation, or, at least, for examining certain points of tension between regional goals and objectives and local performance.

To form a local branch, women at the grass roots apply with Wanawake in the regional capital. The regional leadership asks for a minimum of twenty women before application, but no maximum number is established. The women are asked to pay a contribution of 1000 shillings per month (one US$).[29] Seventy-five per cent of the fees are to be spent by the group itself, whereas twenty-five per cent goes to the head office. The collected money is meant to support projects that the Wanawakes choose to organise in their community.

Each local branch has a Chair person, a secretary, someone responsible for HBC and orphan care, and a finance officer. The chair and the secretary are elected by the members. The chair is responsible for maintaining contact with the district and regional coordinators, and is expected to participate in additional trainings, workshops, and district and regional activities.

Training

When the local women and the regional umbrella agree on the conditions of participation, the new group will receive a training of five days, delivered in their village. The training consists of organisational procedures such as the constitution of the organisation and other institutional arrangements, but also the Wanawake motto and its values. Cultivating a common identity based on solidarity with the community and its HIV related problems is highly valued and enacted through song and dance. The training includes a short course on Community Based Counselling. The idea is that the new members group themselves into teams to deal with three different areas: Home Based Care, HIV-Health team, and an Orphan Identification team. The training is given to a maximum of twenty women, as the organisation has no greater capacity. If more members are interested, then the trained women of the new group are supposed to teach the other members.[30] Specific or additional trainings after the first introduction are offered at the head office in the regional capital. These are attended

---

[29] Wanawake Upendo Migule, Minute book 2003-2005.
[30] HBC programme coordinator, 04-04-2005

by the chairpersons of the local branches, and perhaps one or two appointed members. Again, they are expected to transmit everything they learn to their local members.

In practice, the chain of information and training is not as strong as envisioned. As the HBC programme coordinator at the head office observed, many women's groups at the grass roots are not very good in 'copying' training and information to their members, and face a problem as there is no money for continuous follow-up training supplied by the head office. The Migule-case confirms her concerns.

The leadership in Migule confirmed that their members did not have enough knowledge. They blamed this lack of training for their limited activities on the HBC and prevention front. When asked about training, they gave a similar response to that given by the Village Health Workers: they did not know enough because they had not received sufficient training. The quest for more training, however, is not directly related to the knowledge itself, rather, to formal recognition of such knowledge, on the one hand, and assumed external support attached to training, on the other. Medical knowledge in itself should not be the problem as this was represented by doctor Mwinyi, an STI expert, district health officer, and member of Wanawake Migule. Nevertheless, to be valid, a *formal* recognition of the transmission of such knowledge needed to be organised in the form of 'training', which, in general, is an event that recognises abilities required in the form of status capital. Formal training also confirms institutional links and the networks attached to such institutions, be that in the form of (international) funding bodies and research groups or local leaders. The prevailing 'seminar culture' –an institutionalised form of learning in lack of a solid and inclusive educational system or access to independent forms of learning- underpins such notions of how knowledge is validated.

Motivations to participate: professional concern, self-interest, and solidarity

The individual motivations of people who participate in community activities are important to understand the effectiveness of such participation. Therefore, examining the motivations and expectations of the community-workers involved also helps to understand the conflicts of interest that might exist.

In order to disentangle the different expectations and interpretations of what participation in an HIV/AIDS community project entails, we will examine the motivations of the community-based workers themselves. Why do people such as the district coordinator (Mrs Amina), Mrs Majogo or the nurses Yomba and Mwinyi volunteer in an organisation such as Wanawake? Personal conversations and timely reconstructions shed a dim light upon these issues. Given that motivations are built upon a string of personal interests not always visible in limited conversations, this analysis can only provide a limited understanding of volunteers' motivations to participate in community action. Nevertheless, we believe that such an attempt must be made in order to increase our understanding of participation and its contradictions. The following three close-ups are individual stories, but also represent the most obvious of motivations in this kind of community work: self-interest, professionalism and solidarity.

The professional

Mrs. Amina, an educated, English-speaking woman in her early forties, is the coordinator of Wanawake in the District. She is not a volunteer, but is paid to coordinate, support, and represent the grass roots groups in the district. Although Mrs Amina is obviously dedicated to the cause, she would not have taken this job on if it would not have been paid. This is no surprise as this is a full-time job to support and coordinate the many local groups (at least eleven). Amina said she liked the job because she likes to work for people and especially because she wants and likes to help the increasing numbers of orphans. The most difficult part of the job she found to be the volunteering women at the grass roots, the envy and many misunderstandings she encountered among them. However, relying on the opinions of the local groups and beneficiaries, Anna Amina was dealing very well with such conflicts, as everyone respects and likes her. Her motivation for participating in Wanawake is not altruistic, but her work is, in return, professional and respected as such.

Personal interests

Mrs Majogo is one of the founders of Wanawake-Migule and is a sturdy woman with several grown-up children. Given her economic situation, the fact that she is a teacher and doubtless her well established contacts with the influential doctor Mwinyi (who is the chair of the ward committee and of various educational, medical, and political

institutions in Migule), she has an authoritative position in the community. In relation to her volunteering work, Mrs Majogo claims that she was always very interested in helping her neighbours and did so in other CBOs before they set up Wanawake in Migule. Her various activities and her connections indicate that she is indeed concerned with community development. Her self-imposed distance from other community-members, however, also suggested a strong necessity for hierarchy. Mrs. Majogo's position in the community as a relatively well-off teacher and her connections with the governing elite of the village is strengthened by her chairing the women's initiative against AIDS. As such, Mrs. Majogo fits the image of the elite woman who helps and supports her neighbours out of a maternalist duty linked to the reproduction of otherwise ill-defined class boundaries. As Bujra rightfully observes (2000: 155-156), whereas AIDS related charity and activism often confirm such class boundaries –rather than challenge men's behaviour out of female solidarity, for example-, this does not discard women's concern for and commitment to the dying and the destitute. Nevertheless, such class-based charity can easily be interpreted as 'greedy' or 'power seeking' by those less fortunate. Class differences are based on a variety of determinants such as education, networks, political influence, and economic position. However, this does not mean that there is no tension between 'volunteerism and personal financial need, as well as between personal commitment and inadequate organisational resources' (Bujra and Baileys 2000: 42).

Setting up Wanawake-Migule coincided with the start of the World Food Programme (WFP) of foodstuff support to HIV affected families. As an incentive to the distribution volunteers, the leaders of local Wanawake branches are allocated a part of the foodstuffs. As I will discuss in more detail below, the allocation of WFP support has generated all kinds of unforeseen activity and conflict in which Mrs Majogo plays a crucial role that indicates her economic interest in being a volunteer for Wanawake as well. For Mrs Majogo, her commitment to volunteering in Wanawake seems to include a desire for maintaining and expanding status capital and, to a certain extent, access to resources.

Solidarity, professionalism, and self interest

Nurse Yomba has a different story. She worked as a nurse in the District hospital and, in 1996, applied and was selected to become a specialised HIV counsellor. Wanawake

provided for a six-week training facility for nurses in the district to become such counsellors. Nurse Yomba likes her job very much as she likes to teach the different groups in the community about all subjects related to HIV/AIDS. While doing the Wanawake training, she also became a member of the women's organisation. As a professional, however, she expects to be paid for the work she does as a teacher, even if she trains her fellow volunteers at Wanawake. In other words, she is keen on working for and with HIV/AIDS affected people and patients as a professional, and also as a community member –for free if necessary. However, she also expects returns for her professionalism, especially when external bodies (NGOs, international organisations, government) ask her to participate in capacity-building activities.

During our fieldwork, Nurse Yomba and doctor Mwinyi both showed little initiative, and little volunteering spirit, in sharing their knowledge with their fellow volunteers. Although this suggests ambivalence between volunteering and being paid, it can also mean that both are protective of their professionalism. They are happy to use their professionalism to help people with medical problems, for free if necessary, but less so to teach others how to become semi-professional. As do most AIDS activists, Nurse Yomba is genuinely committed to fighting against AIDS in her community. She wants to do more than the hospital she works for can offer and volunteers in her free time. However, she would probably prefer to be recognised, and paid, for her professionalism as a HIV/AIDS counsellor. The rise of NGOs and CBOs, and the simultaneous withdrawal of the state, suggest that professionals like nurse Yomba could initiate activities for which they should be paid.

Food support, voluntarism, and conflict

In 2003, the World Food Program agreed to provide food support to families affected by HIV/AIDS using Wanawake as a distribution network.[31] The Wanawake head office proposed a basket of maize, mixed cereals, cooking oil, and a blend of corn soy for a whole year and per selected family. Wanawake receives the foodstuff in bulk twice yearly, and distribute this among their branches. The amount of baskets local

---

[31] WFP policy is explained in: the Country Programme Activity Summary, Tanzania, 2002-2006. An interview with Assumpta Rwechungura, coordinator at WFP in Dar es Salaam, provides for additional information.

branches receive is determined by the applications that each branch handed in at the beginning of the programme, in 2003. According to the Wanawake head office, this list cannot be expanded to include new people. Migule handed in a list of nine people with HIV/AIDS and twenty families with orphans to care for. As people increasingly came forward as being victims of or affected by HIV, conflicts arose over these portions, selection procedures, and quantity.

As soon as the availability of foodstuff distribution became known, the amount of applications increased rapidly. On the positive side, this has led to more and more people testing for HIV/AIDS, and more and more people being open about it. On the negative side, the WFP/Wanawake food-support programme was not prepared to accommodate increasing numbers of people. This generated many conflicts among people and among groups. According to the deputy executive coordinator of Wanawake in the regional capital, at the start of the programme in 2003, some 80 families were supported by the programme; in a very short time, there were 200 more. In January 2005, 700 PLHA were registered with Wanawake, in April there were a 1000. At the free testing service that the head office of Wanawake offers, 15 people a day were seen. According to staff, infection rates were still increasing.[32] However, it is not clear if the actual rate of infection is increasing, or if more people come for voluntary testing. If the last is true, then we should seriously ask to what extend the food-support scheme influences people's motivation for voluntary testing, and to what extend food aid can support a HIV affected family in the long-run. The relation between poverty, hunger, HIV infection rates and AIDS deaths seems obvious. WFP intends to address such issues; however, as we will see below, this generates so many conflicts that perhaps the strategy should be reconsidered.

The Migule case study is a good example of the type of animosities that can occur among and between beneficiaries and food-distributors over allocation of resources. Although selection procedures of potential beneficiaries are community-based and participatory, the beneficiaries, and especially those who have been left out, accuse the Wanawake leadership of corruption and nepotism. The Wanawake leadership tried to solve problems by dividing the portions among more people; however, this

---

[32] Interview with the Deputy executive coordinator, 04-04-05.

generated the accusation of stealing from assigned baskets for their own benefit. The conflicts are heightened by the personalised management of Wanawake-Migule, and the suggested clientelism expressed by the leadership in its distribution of the baskets.

Here, the close relation between the respected community-leader doctor Mwinyi and the Wanawake chairperson Mrs Majogo, reinforces the image of elite-capture, clientelism, and corruption. Their inability to account for their actions and decisions in a participatory way and the increasing vulnerability of several families has raised the tension around the food distributions. While conflict seems to have existed before, the food distributions increased tensions considerably.[33]

Selection procedures

The above raises the question of what the official and actual selection criteria of becoming a WFP recipient are, and how these are received by the CBWs and the beneficiaries. To start at the top, WFP first selects a partner organisation in the region. They do so based on official registration, the organisations' ability to provide complementary services to the beneficiaries, and on the recommendation of local authorities.[34] In the region, WFP selected Wanawake. Selection of individual beneficiaries is based on household food insecurity. 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, or who care for orphans. This is still too long a list. Therefore, the 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

---

[33] The fieldwork has shown that Mrs Majogo did indeed lie and cheat about the distributions, for whatever reason.
[34] Email conversation with Assumpta Rwechungura, WFP coordinator, Dar es Salaam, 29/11/05.

those who do 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 PLHA (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. 3) Wanawake regional leadership, ie, 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 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.

Issues of power and hierarchy within Wanawake and beyond

The hierarchy among Wanawake members and workers seem to be established along lines of education and socio-economic position.[35] This rather obvious hierarchy runs from the regional office of highly educated, English speaking, salaried coordinators, to less powerful district officers, to branch chairpersons, to branch committee members all the way to those members who are HIV-positive. The institutional structure is also organised in such a way: the coordinators from the head office decide over the districts and eventually, over the villages. The head office manages the budget: the District office does not manage any budget. This means that the district coordinator has little freedom of movement concerning local projects, needs, and workshops.

Politicised hierarchy

Wanawake being a women's organisation, men are in principle non-voting advisors and volunteer workers. However, the Migule case study suggest that men can hold implicit power that could influence the activities and decisions made by the women-

---

[35] Bujra and Mokake (2000: 164-165) analyse the relationship between those formally seen as 'equal members' of another Tanzanian women's organisation against AIDS, Wamata, as a complex web of understandings between what is ultimately seen as relationships between 'client and worker', or (paid) staff and the poor and powerless.

only directive committees of Wanawake local branches. Leadership is often invested in the same persons, a small group of women and men who rotate community responsibilities amongst themselves. Subsequently, such local leadership knows their place: a strict and politicised hierarchy is assumed among all layers, from beneficiary to local leader, to village leadership, to ward and so forth.[36] Green (2006) observes that these hierarchies are highly politicised as access to resources can only be achieved through access to political leadership. To be able to access resources at a local level, access to and being part of local political leadership is thus essential. As Bujra observes (2000a: 129-130), the resulting unquestioned leadership can lead more easily to corruption as accountability is not expected. Such local corruption is also rarely exposed. However, the issue of food distribution seems to have touched upon a sensitive issue: in the studied case, a group of PLHA with nothing to loose protested against the selection and distribution procedures which are normally not scrutinised. The organisation is now forced to change not only their procedures, but also the style of leadership at the local level if the issue of food distribution is to become a peaceful process.[37]

Conflict between CBWs and PLHA

Then there is still another highly problematic and –perhaps- more disturbing hierarchy: the balance of power between what we have identified as Community Based Workers on the one hand, and those who are referred to as PLHA on the other. Many PLHA indicated feeling treated as inferiors, not being taken seriously, and pushed into a situation of dependency. If we look at the make-up of the different committees and organisations dealing with issues related to HIV/AIDS, we have to conclude that a small minority were actually PLHA, and those who did take part were often pushed into inferior positions. An aura of dependency and helplessness surrounded those who were actually HIV-positive. Kiwakukki-Migule counted with several people who tested positive, but who are not open about it even within the organisation. In addition, several PLHA suggested that while they were often pushed forward to give talks, show their faces, be present as 'confessional examples', they were never consulted about proceedings and activities and did not feel included.

---

[36] This is a legacy of Nyerere's one-party socialism.
[37] The group of PLHA is also divided on the issue: only one or two members openly denounce Wanawake's practices, while the majority prefer to stay quiet out of fear of loosing the little support they still receive. They do support this one complaining person, when necessary also in public.

Several organised PLHA suggested that the present CBWs were corrupt because in the end they 'did not know and did not care' what it means to be ill and dying. As a result, a lobby for more involvement of PLHA in grass roots policy with regard to HIV/AIDS care and prevention seems to have sprung up.

IV. Kikume: PLHA against AIDS

The third and last community-based initiative to look at that deals with HIV/AIDS in Migule, is an organisation of people living with HIV/AIDS. This is a relatively new phenomenon, but increasingly important. Globally, organisations of PLHA are increasingly recognised as crucial to the success of the response to the pandemic, as well as to the wellbeing of people living with HIV (APN+ 2004; Manchester 2004; Robins 2005; Global Movement 2005). Nevertheless, there are also multiple social problems with including PLHA in the response to AIDS, most of which are strongly related to the prevailing stigma worldwide.

In Tanzania, PLHA have started to organise since the early 2000s. They did so following examples from successful initiatives in Uganda and Kenya. In addition, NGOs and CBOs have realised that they need to do something *with* the group they target, not only *for* them. The perception of PLHA is often a misconceived vision of a poor and ill victim in urgent need of help and support. Although many indeed need urgent help and support, they are also persons with a life prior to contracting HIV/AIDS, a life which is all too often destroyed. Therefore, groups of PLHA that focus on mutual emotional, social, and sometimes economic support are set up everywhere. These groups often focus on a concept known as 'living with hope', ie, turning the depressing fatality of the situation, both on physical and social levels, into a positive future, a bearable life (Manchester 2004). Migule has one of the vanguard organisations of PLHA in the region, called KIKUME (Kikundi Cha Kupambana na Ukimwi Migule, Group Fighting Against Aids in Migule).

Institutional arrangements

Kikume was founded in 2002 following examples from the cities of the regional capital and Tanga. The first goal of Kikume was to provide HIV education. With time, Kikume expanded its activities with vocational training for orphans, the building of an orphanage house (in close cooperation with Wanawake), providing voluntary testing and counselling facilities (carried out by the mobile services of the District hospital),

condom distribution (donated by a Japanese company) and distribution of some basic medicines. They also provide home based care.

Just as in Wanawake, Kikume has some twenty members and many beneficiaries, but thrives upon the activities of a small core group of active volunteers.[38] As they were central to this research, and have contributed exponentially, they need a short introduction: The founder of the organisation, Mr Joseph, is respected and consulted by the younger chairman, Mr Msinga. Mr Msinga was born in 1976 and discovered he was HIV-positive in 2003. He and his also HIV-positive wife are active not only at the community-level, but intend to spread their activities throughout the district and indeed the region and the country. Mr Msinga has also been central to the establishment of a national men's organisation against HIV/AIDS, Movement of Men Against AIDS in Tanzania, MMAAT. Apart from being active Kikume members, the Msingas take care of two children as well as three orphans left behind by friends. Mr and Mrs Msinga have finished some secondary education and speak a little English. They earn their living with professional photography. Unfortunately, this is a difficult profession in this poverty-stricken district. Nevertheless, they seem to manage doing the odd marriage and birthday assignment.

The secretary of Kikume is Mr Kipingu. Mr Kipingu is very committed to the organisation, for reasons explained below, but his household is in an increasingly difficult position. He and his wife have five small children, a mother and a grandmother to care for, and five more small children left behind by a brother. Mrs Kipingu is increasingly suffering of opportunistic diseases. Mr Kipingu, a carpenter by profession, rarely receives any assignments, and even if he would, he would not have the capital to invest in materials and equipment. Their survival seems to depend on odd jobs, a little agriculture, and external support. Mr and Mrs Kipingu have not finished primary school.

The leadership composition of the organisation shows that Kikume is a local organisation, set up by local people, even if they follow national and international

---

[38] These CBWs have participated fully in this research and have indicated that they wanted to be mentioned by name in everything they have said. Therefore, this is the only section in which informants are identified.

examples. They apply for and receive donations in money or in kind, and maintain networks with other interested organisations in Migule and beyond. Kikume might be called a successful example of institutional 'bricolage' (Cleaver 2002). The organisation manages to balance local with national and even international networks, accepted new forms of institutional hierarchy, communication and organisation, and, especially, they manage to build bridges between PLHA and authorities at different political and institutional levels. This is a major achievement considering the widespread stigma attached to HIV/AIDS, the local conflicts over access to resources and decision making power, and the reluctance to implement comprehensive policies for the prevention of HIV and care for the chronically ill on the part of the village elites.

Sustainability

As an organisation, Kikume has two major problems. First, they have no income as an organisation and very little as individuals or families, which makes it very difficult to self-finance activities. As a result, Kikume is largely dependent on external funding. The Village Council donated 150.000 TZS, but, as Mr Msigna claims, after that donation they have not provided any support to Kikume and have not repeated their generosity. Rather, Kikume relies on donations from organisations such as Femina International, NOVIB, OXFAM, World Vision, and local NGOs such as Saipro. These organisations do not provide long-term funding, rather, they provide materials such as condoms, sewing machines, leaflets, food, and medicines. These donations are not always useful; for example, the donated condoms are unwanted by the majority of community members because they are made of too heavy plastics and not transparent. Unfortunately, this large box with hundreds of condoms is wasted because they are not the right material or colour. Recently, Saipro selected Kikume for a programme in which they provide a loan and support to set up a small agricultural business. Such a project could be the start of a more sustainable form of income generation. In addition, one organisation has helped out with obtaining a piece of land just outside Migule, on which Kikume has started the building of a centre for people living with

and affected by HIV/AIDS. Despite the difficult economic position the members find themselves in, each one contributed 20.000 TZS to the project. [39]

This brings us to the second major obstacle to Kikume as an organisation of PLHA: the organisation largely depends on dedicated people who, without access to medicine, will probably die within the next two to five years. This can obstruct continuity as an organisation. Perhaps, donors' preference to fund immediate necessities instead of long-term ones is related to this bleak future. The leaders of the organisation, Joseph (founder), Kipingu (secretary), and Msinga (present chair) and his wife Joyce Msinga (HBC coordinator), have identified this as an organisational weakness and actively recruit HIV-negative people to become members. As such, several nurses from the government dispensary are active Kikume members, as well as other individuals active in the community.

Despite these difficulties, Kikume is successful in many ways. The organisation participates in all relevant local organisational structures such as the ward-level Development Committee, Wanawake, and other institutions nation-wide. They can also partly rely on the goodwill of others; the Kikume office is located in a building owned by a doctor from the regional capital, native to Migule, who lent it to Kikume. However, the landlord intends to turn the building into a guesthouse, which means that Kikume has to move out.

Motivations to participate: Depression and the search of a future
The motivations of PLHA to participate in HIV/AIDS care and prevention in their community could seem more 'genuine' than those of paid health care workers or the members of organisations such as Wanawake. As will become clear, the motivations of PLHA to participate in this group are highly personal, while at the same time, strongly related to the wellbeing of the community. This apparent contradiction does

---

[39] This is largely based on interviews with Mr Kipingu, secretary, and Mr. Msinga, chairperson of Kikume. Kikume's success includes attracting more funding for the project; recently several other organisations, including the district government, have promised contributions.

not create conflict, but rather, solidarity, as the Kikume members identify with the misfortunes of their beneficiaries.[40]

The main motivating factor that explains PLHAs willingness to participate seems to be their personal desperation. For example, Mr Msinga told us 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 PLHA 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 Kikume in Migule. Msinga suggests that his activism not only help 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.[41] PLHA are physically threatened by HIV and then 'prematurely' neglected by their surroundings (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. But 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 PLHA-group Tumaeni, in the District capital, helped her to be busy, make plans, and feel supported by other PLHA.[42]

The lack of a future, apart from the view on a near and depressing future leading to an inevitable death, contributes to HIV-positive people's depression on the one hand, and their motivations to be active in community work on the other. Making plans to improve the situation in the community, to prevent others from getting infected, and

---

[40] Most organised PLHA came up with this 'we know how it feels', and even, 'we know what to do and how to fight'.
[41] Group discussion with Anna Gilbert Kobela, Flora Matumika and Dora Stefano, members of the Tumaeni PLHWA organisation in the district capital, 30-03-05.
[42] Idem.

to improve the facilities and services for present and future victims of HIV and those they leave behind, seems to give many PLHA a strong incentive to look forward again –although in service of the community and not their own, personal, future (Manchester 2004). The future of their children is incorporated in such a vision: both Msinga and Kipingu explicitly stated they hoped to give their children a future. PLHAs' foretold deaths make their children 'premature orphans' as well. Therefore, the provisions they try to establish in the community to take care of orphans should be directly linked to their own wish to provide a future for their children when they are not there anymore.

This partly explains, of course, Kikume's active concern for orphans. By building facilities for orphans in their community, they are also creating possibilities for their own children. They are actively trying to provide housing for orphans, as that is their own family-worry as well. Not all children have an extended family left to take care of them; grandmothers die too, sisters and brothers as well.[43] Kikume also provides extensive training for children, carpentry for boys, tailoring for girls, aiming at making the children independent as soon (and as early) as possible. Their vocational training does not depend on the Kikume members, but on the children themselves: the oldest and most skilled commit themselves to teaching the younger ones, until they take over and so forth. Equipment is sometimes provided by World Vision, materials are an investment when assignments arrive. The children, the Kikume volunteers, and the family members of both form a strong community. At the same time, they form an open community and make clear to their neighbours that everyone is welcome to join. As such, the commitment of Kikume CBWs is strong and sincere; however, they also have their own, personal reasons why they do what they do.

---

[43] The interviews with people living with HIV showed that a majority take care of their own children and of others'. Some take care of the children of several deceased brothers and sisters, plus aging mothers. Such families are rapidly out of their economic possibilities to take care of everyone, as small children, elderly people, and sick family members place a heavy burden on any savings or otherwise economic flexibility.

Stigma and exclusion

As we discussed above, stigma and social exclusion is one of the main reasons for the depression in which PLHA often enter when they learn about their health status. Not only their inevitable physical decline, but, in particular, social exclusion (including increasing difficulties to engage in the economic process as a result of rejection and physical vulnerability), public stigma, and the impossibility to provide for their children are major concerns. By organising in a group identified by the very cause of their exclusion, they force the community to look, to engage, to admit their fears and relations, and to acknowledge that HIV-positive neighbours are indeed still the same human beings as before.

However, this public recognition of health status is not always positive: all our informants claim to suffer from prejudice on a daily basis. In addition, although as a group they have strengthened their position in the community considerably, the group of organised PLHA in Migule are still on the lower steps of the strict hierarchy that rules the town (and Tanzania). This is partly because of the existing politicised hierarchy as discussed above. The condescension for PLHA shown by elite members of the community is related to education and socio-economic status: none of the Kikume members had previous leadership positions in the community and none speaks English (an important indication of education level, and thus status). In addition, as we saw above, even among those who work to support and help in the efforts to set up prevention and care mechanisms, prejudice against PLHA persists (also: Manchester 2004).

Besides the existing stigma and the tendencies for exclusion by some community members, other community members realise that what happened to their friends and neighbours could easily have happened to them. As noted above, in 2004-05, Wanawake-Migule and Kikume joined their forces to build a house for a grandmother and several of her grandchildren who had been left behind after their parents had died of AIDS-related diseases. The two CBOs contributed to the funds to buy materials; the neighbours put in their labour. As such, as the leadership of Kikume also admits, many neighbours realise how precarious their situation is, with the threat of HIV/AIDS in the midst of their community, and are prepared to join forces to help each other out.

Conflicts among PLHA and beneficiaries

Although we have sketched a somewhat ideal group of committed PLHA who work in solidarity for their families and their communities, we also need to look at the conflicts that arise within these groups of activists and beneficiaries.

Denying disaster

The active members of Kikume, the Msingas, Kipingu and one or two others, also perform outreach tasks. They visit houses where they know or have very strong suspicion that householders are infected with HIV. As their networks are strong, and these include medical personnel, in general the Kikume leadership knows which neighbours are victims. However, not all neighbours want to know their health status. Several of our and their fieldwork notes show that their outreach work was sometimes met with anger. In one case, a very ill mother was called upon to see if she needed anything such as medicines to treat opportunistic diseases. Her grown up son kicked the Kikume delegation out rather violently, negating the necessity for help or the presence of any health problem in the family. One of the Kikume members managed to speak to the woman in private on another occasion, and concluded that this resistance for help did not come from her, but rather from the son. The fear and shame attached to the disease breaks up families such as these and prevents people from seeking available help.

The interviews the research team made with PLHA in one particular neighbourhood were also the object of gossip and mutual resentment. Although the research team did everything to verify stories by cross checking, the gossip did show the difficulties which surround HIV, activism, and especially, openness about one's status and the cause of death of family members. HIV affects people's worse social fears, and as such, these fears are also part and parcel of the organisation of people living with HIV/AIDS, despite their efforts to be as open, sincere, and respectful as they can.

Envy over resources

The increasing support available for PLHA 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. One of our informants, Mrs Msinga, wrote in her diary 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. Given the reputation of being helpful and generous on the one hand, and the existing belief that the Msingas receive funding from outside, more children arrive at their doorsteps in search for their help.[44]

Although this could appear to be a single negative example, anecdotal evidence suggests that such animosities are widespread. Stigma prevails in families, interviews held and diaries written for this research show that people fear telling their situation to family members, and when they do, are all too often ostracised, abused, and excluded. Most HIV-positive people are cared for by family members, but often in extremely isolated situations. Sometimes, AIDS patients are hidden away and offered basic palliative care until death arrives. The issue of external support sometimes exacerbates the situation, cutting people off from kinship networks, generating envy, and risking violence from family members. In all, although vital for some, external support can contribute to the weakening of the social fabric necessary for the functioning of community projects with regard to HIV/AIDS.

Transparency and accountability

The issue of financial accountability is the more important in this group of destitute people who rely heavily on mutual solidarity and social and emotional support for survival. Conflicts over money are likely to ruin the set up of the organisation

---

[44] Mrs Msinga, diary 10/7, 13/07, 14/7 2005.

(whereas in the case of Wanawake, members have interests beyond the main goal of 'helping others' and are neither emotionally nor socially dependent on each other. Rather, hierarchy and status helps to maintain their dealings, including access to resources). The Kikume leadership seems to realise that a lack of transparency would undermine their strength, and their access to international resources. Therefore, they keep accounts, report back, and decide jointly and participatory on the destination of incoming funds. Whereas in our observation, including the cross-checking of gossip, this seems to function exceptionally well, the transparent system also seems to rely heavily on good leadership. As in any newly created organisation, it is not yet clear if Kikume can sustain its reputation in the long run.[45]

---

[45] A follow up on the transparency and accountability of Kikume and Wanawake will be carried out in July-August of 2006.

Table 1: Characteristics of CBW studied systems, shows a table which summarizes the comparative characteristics of the studied CBOs in Migule, the Village Health Workers programme, the Wanawake volunteers, and the initiative of PLHA, Kikume.

Graph 2, Institutional web, shows a diagram of the available institutionalised (formal) supportive network for vulnerable community members. The size of the boxes has nothing to do with the importance of related institutions. Rather, the four centre stage ovals are the main players in this study, while the outer circle (yellow) represents international stakeholders, towards the inside, national (red), regional (blue), district (purple) and village (mint) stakeholders. This visualisation suggests that there are many facilities for vulnerable groups, including for PLHA. However, this is deceptive as there is little organisational overview or management, and little resources to distribute. Possible coordinators of all this activity, such as the village and ward councils, have little interests in protecting the vulnerable.

While the international organisations distribute funds to national and regional organisations, the community-based organisations receive very little of this money. TACAIDS funds get stuck on regional level; international funds often as well.

Graph 3: Government structure for HIV/AIDS prevention and care, shows a diagram of the government's multi-sectoral framework. Again, the visualisation shows how resources and knowledge *should* trickle down. However, we have seen that little of the resources available at the top of the diagram actually reach the bottom, where the community-based volunteers operate.

Graph 4: Informal structures and process, summarizes the informal factors that influence AIDS transmission, prevention and care in Migule. Whereas issues such as the drugs production, trade, and consumption or the sex industry are specific to Migule, many of the imperatives –poverty, gender inequality, and politicised hierarchies, or status quo- are far more general. Each community will undergo different effects, but they will, in most such cases, negatively affect both the prevention of AIDS and the care for its victims. The bottom line of the diagram shows the community's social safety nets.

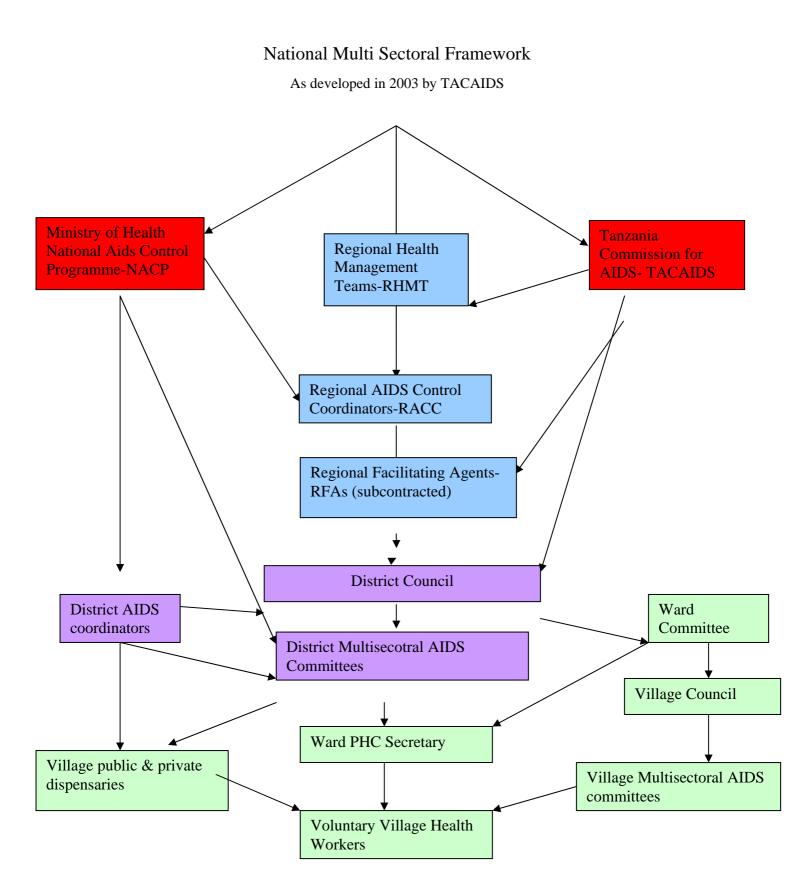| Inst itutional Origins	Facilitating Agent	Selection Criteria	Community accountability	Incentives/ motivation	Mechanisms of in/ exclusion	Reach	Tasks
Village Health Workers Successive institutions since early 1980s: Marie Stopes, Catholic Church, World Vision, State	State: district/ward/ village dispensary	appointed by popular vote per subvillage	To dispensary personnel and neighbours	Promised but not arrived 15,000 Tsh a month, bicycle for some, personal motivation in leadership position. Status capital	Of VHW selection: those who have a leadership position; of beneficiaries: those who are open and receptive to VHW	Two VHW per subvillage	Officially: Hygiene & sanitation awareness& care, HBC activities (unclear), informing the dispensary personnel on developments Actually: Everything but HBC
Wanawake 1991 women's initiative to organise against AIDS	Local group supported by regional Wanawake Organisation, in turn financed by Internat. funders	Voluntary joining. Must be women; have to pay monthly contribution + attend meetings.	To Wanawake The regional capital; to Ward secretary; to honorary members (often esteemed male community members); in principle to PLHA, in practice not	Certain material benefits from programmes which allow for an allowance to volunteers, but not much. Status capital	Local leaders have the power to in/exclude both members and beneficiaries. Official procedures to select beneficiaries based on openness and need, but are questionable in practice.	20 volunteers to some 500 orphans and unknown number of PLHA; food prog.: 29 beneficiaries	Officially: HBC activities: economic support; psychological support (Living with Hope), WFP food distribution; orphan support Actually: WFO food distribution, Orphan support.
Kikume 2003: PLHA follow regional examples to organise	Self-organised, self-generated funds with increasing external support, including one-off governmental funding	Voluntary joining. No official criteria. In practice: PLHA, family members of PLHA, nurses & doctors, orphans	To PLHA; to donors; to local government (where involved); to the district (TACAIDS funds allocated through district council)	Personal motives: searching for a future; preparing for illness & death; providing for children. Healthcare professionals: community solidarity & concern	External barrier: stigma (one needs to be open about status to become involved)	Ward-level: education to vulnerable groups Everyone willing to listen; Most directly: neighbourhood PLHA	Officially: Help orphans and PLHA, educate yoth on drugs, educate about family planning, educate about environmental conservation. Prevention and care, solidarity and support. Actually: prevention education, income generation, medicine & condom distribution, HBC, outreach work, emotional support, fighting stigma, care and education for orphans.

2. Institutional Web

3. Government structure for HIV/AIDS prevention and care

National Multi Sectoral Framework

As developed in 2003 by TACAIDS

Ministry of Health National Aids Control Programme-NACP	Regional Health Management Teams-RHMT	Tanzania Commission for AIDS- TACAIDS

Regional AIDS Control Coordinators-RACC

Regional Facilitating Agents-RFAs (subcontracted)

District Council

District AIDS coordinators

District Multisecotral AIDS Committees

Ward Committee

Village Council

Ward PHC Secretary

Village public & private dispensaries

Village Multisectoral AIDS committees

Voluntary Village Health Workers

4. Informal structures and processes

Poverty	Political Status Quo	Gender inequality	International paradigms

Mirungi cultivation, trade & consumption

Lack of political will to change situation

Sex workers

Police corruption

Presence of truck drivers

Lively commercial street activities night and day

Trade in goods siphoned off the traders

Lack of protective legislation or law enforcement

Increasing commercial possibilities

Health problems increase

Health facilities cannot cope

Orphans and poor children first to be affected

HIV/AIDS

Vulnerable people caring for own children + orphans

Sexual Abuse

Community responsibility polarised between risk and gains

Moral divide and stigma emphasised

Ambiguous contribution of Churches & FBO	Increasing responsibility on poor CBOs	Growth of power of witch doctors	Marginal medical services	Weak Kinship ties

V. Recommendations and expectations of the participants in research

Not surprisingly, all CBOs would like to be better funded. Interestingly, Wanawake, the women's organisation, believes that external funding should come from international donors, as they do not expect the state to be generous. The women of Wanawake-Migule also organised their own income generating activities to finance projects. The contact between the local Wanawake leadership and the village/ward leadership was very strong; this did not, however, increase expectations of funding. They knew very well what (not) to expect. Their institutional background confirms such a position: whereas the Wanawake headquarters in the regional capital do not reject collaborating with government, they do not expect much either. In the end, Wanawake counts on the generosity of and good relationships with NGOs and international donors.

On the contrary, the Village Health Workers insist on funding from government institutions, either from the Village Council or the District Council. As they perceive themselves as being part of the political structure of the village, they do not expect nongovernmental funding. Kikume, the organisation for PLHA, has stretched its hopes and possibilities beyond the distinction of governmental or non-governmental. Thanks to the charismatic and thoughtful leadership of the photographer Mr Msinga, Kikume has been able to expand its networks and associations rapidly. Its networks – and its possible material gain- stretch from local governmental institutions to the national institution for HIV/AIDS, TACAIDS. In addition, when they manage to collect some funds, Kikume members travel extensively to the rural communities surrounding Migule in order to raise awareness and create solidarity. They do the same in urban areas in both Migule and in the District capital. Considering the well-functioning, extremely urgent objectives, and the transparency of the organisation, national and international NGOs have also found Kikume increasingly interesting.

In addition, both the Village Health Workers and Wanawake members felt a need for better and more training for both leaders and members. Considering the above discussed vagueness about the contents of training, we might want to interpret this quest for more training as a wish for more institutional guidance. None of the Kikume

members have expressed the need for training in their organisation –apart from the desire to learn English.

For the purpose of this research, several members of the Kikume group have kept a diary over six months. These diaries contain detailed recommendations and desires aimed at improving the situation in their community. These recommendations show a great trust in the responsibility of the state, as all ask for better legislation, guidance and funds on the part of the government. Some of the points that stood out in these deliberations were the quest for equal rights between men and women, better reproductive health and family planning services, better economic opportunities for men, and especially for women (so they will not resort to prostitution), laws against women wearing miniskirts, and regulations against Miss Tanzania elections, nightclubs, dowry payments, female circumcision, and a law that stipulates compulsory testing before marriage. Further, the criminalisation of HIV-transmission, especially in those cases where sexual abuse or deceit is involved, was mentioned.[46] Unemployment and the production and use of drugs were seen as major problems; according to one diary writer, NGOs and CBOs should put their efforts in collective income generating schemes, while the government needed to be firmer in drugs policy. Strikingly, none mentioned the availability of ARVs as a central desire to improve their own lives, or as a mechanism in fighting the epidemic.

In general, abstract institutions such as 'government' or 'NGOs' are set against detailed and daily-life observations such as miniskirts and roaming HIV-positive men. Local institutions such as the police or the Village Council are not mentioned as being responsible for drugs or prostitution policies. This could be the result of the wish not to be specific out of prudence, although in general our informants had very little reticence in this field. Such vagueness about who should be held responsible for local development adds further questions to the effectiveness of community-driven development as a concept.

---

[46] Interviewed people, diary writers and even the research assistants in this research are absolutely confident that there are many HIV-positive men who continue to have sexual relations without using condoms and without being open about their status. After six months in the field, the research assistants could identify which men in the village were infecting others in this way. Criminalisation of HIV transmission is also an increasing concern in Europe, see: http://www.gnpplus.net/criminalisation/intro.shtml

The recommendations of these four Kikume members show to what extent this organisation of PLHA is indeed fighting against the odds. As an organisation they can only set in motion temporary programmes –which lasts as long as the funding lasts- and small scale interventions to protect and care for each other and specific groups such as orphaned children. They are, however, dealing with a situation in which laws do not protect them or their healthy neighbours; with a local and national institutional environment which does not guarantee the implementation of laws or of the distribution of resources; with extreme gender inequality that strongly influences the vulnerability of women to contract AIDS; with large-scale poverty; and with a town that earns its little respite by selling sex, drugs, and smuggled goods. Whatever these organisations of volunteers try to implement and organise, the battle seems lost if the overall situation does not improve rapidly (see figure 4).

VI. Concluding remarks

In this paper, we have examined three community-based initiatives that fight HIVAIDS in a Tanzanian roadside town. Initially, our objective was to examine the practices in voluntary, community-based delivery of home-based care. As the case studies indicate, one of the first problems with the research was the lack of a clearly defined understanding of what HBC is among the CBWs who were supposed to be delivering care. All three organisations formally carried out HBC in their communities, and had an official representative to deal with HBC issues. None of the organisations had a systematic approach to HBC, a clear understanding of what it meant, or even a list of patients to be visited. Why not?

Understandings of home-based care
HBC programmes 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, HBC was meant to give patients the psycho-social support that was greatly needed. In African countries, HBC 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. In some cases, NGOs and/or governments trained community-workers to

help family members in the delivery of HBC (Uys 2002). The differences between the African context and the Western context are, however, often overlooked. 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 addition, the moral economy in which the discourses around sexuality and AIDS developed and the resulting changing sexual taboos and sexual learning, is entirely different in most African countries as compared to the West.[47] Without intending to place a hierarchy upon better or worse types of stigma and social violence towards PLHA, we have to recognise the difference between the stigma that rested upon relatively well-cared for HIV-positive people within the gay-community in the West and HIV-positive people in poverty stricken Africa, where being positive is associated with prostitution in a heterosexual and very unequal world. [48] In sum, the success of HBC in 1980s and 1990s Europe and US rested upon different assumptions with regard to the social world and the moral economy, and with regard to what 'cost-effectiveness' meant in medical terms.

HBC includes two basic tasks: administering medicines to reduce hospital visits, and psychosocial support, including small domestic tasks. However, in the above discussed case studies there are no appropriate health care services and only few medicines. Treating opportunistic diseases or symptom control is out of reach of the CBWs in Migule.[49] So what did the CBWs in Migule think of HBC? For the Village Health Workers and for the Wanawake CBWs, HBC meant 'counselling', a concept that included dietary and hygiene advice and was sometimes complemented with carrying out small domestic tasks or handing out small foodstuffs. Emotional or social support was formally included in the definition of HBC, but did not seem to result in

---

[47] Philip Setel observed that, in Kilimanjaro, HIV/AIDS was often perceived as a symptom of a cultural crisis (1996: 1169). Shanti A. Parikh, looking at Uganda, observes a bifurcation of sexual risk on the one hand, and pleasure on the other. A simultaneous medicalisation and commercialisation of sexuality, immersed in the risk/pleasure binary, creates confusion and insecurity over sexual learning among young adults and their tutors (2005: 125-158).

[48] When comparing the situation in the US, Europe and Africa, it is often overlooked that the AIDS epidemic in the North made most victims within the gay community; a community with its own characteristics and sense of community, and contributing in its own way to processes of changing sexual taboos. In a sense, HIV/AIDS has contributed to the strengthening of the gay community, which also released solidarity. The African communities of PLHA, which call themselves 'communities of hope' are trying to create similar forms of identification and solidarity.

[49] HBC programmes in South Africa provide a different example. See case study on RSA and also Uys (2002).

increased sensibility for people's suffering. No interviewed PLHA recognised the VHWs or the Wanawake CBWs as providing social support.

For the Kikume CBWs, HBC was still less defined. The volunteers assumed a caretaking role towards each other (emotional, material, social care and exchange of useful information) and an outreach role towards fellow PLHA who had not gone public (yet). Sometimes Kikume administers medicines to treat opportunistic diseases, which they distribute with the help of two specialised nurses at the government dispensary who are also active members of Kikume. However, this depended entirely on the availability of such medicines. The Kikume members did not separate HBC from other tasks –such as prevention activities or outreach-, but did recognise its formal use: officially, they had a HBC representative, just as the VHW and Wanawake had. This formal inclusion of an HBC task in these CBOs indicates the awareness these CBOs have of international paradigms with regard to HIV/AIDS.

As such, a formal institutional network of donors expects the CBWs to carry out HBC, while at a local level, most people realise that this is an illusion. The medical assistant at the government dispensary –the person who should be aware of the HBC programmes in Migule and who was responsible for several training programmes in VCT and HBC offered by the EU- could not mention any patients under the care of the VHW, 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? Bicycles handed out by one of the previous donors meant to serve for doctors, nurses, and VHWs home-visits, often broke down, where difficult and expensive to fix, and were useless for visiting people in remote areas. Several PLHA also suggested that it was impossible to expect fulltime medical personnel to perform home-based care as well. They knew this was an illusion.

This brings us to formulate the following hypothesis: medical personnel in resource poor settings cannot be expected to perform HBC, or to support voluntary staff, as medicines or treatment are not consistently available. Voluntary staff can only contribute to the distribution of knowledge with regard to hygiene and dietary issues – although both are equally difficult to promote among households that experience a downward spiral of poverty as a result of AIDS. The emotional and social support that

was central in Western community-based HBC-programmes is not reflected in the African moral economy. Although organisations such as Wanawake have shown great solidarity, creativity, and perseverance in setting up facilities for those affected by HIV/AIDS, at a local, community level, such solidarity seems more limited. As yet, in Tanzanian rural communities where heterosexual intercourse is the main mode of HIV transmission, AIDS still points at peoples social fears, at moral decline and misbehaviour, and at individual responsibility for ones health status. Maintaining consistent, non-prejudiced solidarity with HIV/AIDS patients does not seem to reach beyond the community of PLHA.

Autonomy, responsibility, accountability, and professionalisation

In our literature review about community-based workers, we identified four core points in need of further attention with regard the functioning of CBWs. (autonomy, responsibility, accountability, and professionalisation) (Boesten 2005). These four issues were derived from identified problems which had not received sufficient attention in the revised literature. Below we discuss how this case study fits in these four themes.

Autonomy

Our assumption from the literature review was that, in general, 'CBWs are highly dependent on external institutions for training, resource support, and supervision, which undermine the assumption that CBWs can shape the delivery of services according to the wishes, needs, and demands of the community. CBWs are effectively workers in exogenous development interventions.' Our case study partially confirms such a statement.

In the case of the VHWs, they are entirely dependent on government institutions for their appointment, supervision, resources, and training. Theoretically, they could –and did- diversify their sources of support by approaching (or by being approached by) international NGOs and FBOs. However, as they have been appointed under the new multi-sectoral framework, but without actual practical support, their status is identified with the political hierarchy. Therefore, the VHW depend largely on political alliances.

The women of Wanawake are more autonomous than the VHWs: they have decided to be volunteers; they do so because of a mixture of motivations such as solidarity, economic interest, and status capital, and, as members of this women's organisation, not only aim at helping others, but also themselves. Their participation involves income generating activities and socio-political lobbying which is useful for them as a group, as individuals, and, also for a selected group of beneficiaries. Nevertheless, to carry out the tasks as set out by the head quarters of Wanawake, they are largely dependent on external support, just as the head quarters are dependent on international funding. This creates a reverberation of international paradigms such as home-based care, which cannot function autonomously in the setting described above. Therefore, instead of criticising the lack of HBC activity among the Wanawake volunteers, perhaps we should criticise the international paradigm.

The Kikume members have yet different issues with regard to autonomy as an organisation. Their capacity to organise and carry out the objectives they aim for is partly dependent on external funding. At the time of this research, the organisation was at a turning point of learning how to deal with external funding bodies, and how to adapt to national and international paradigms. Kikume was autonomous and entirely self-organised, but will become increasingly dependent on such paradigms as they will have to comply with increasing external demands with regard to tasks and accountability.

Responsibility

With regard to 'responsibility', we held that 'CBWs dependency on external agents, be that NGOs or state institutions, undermines the idea that the community could 'own' the solutions to their problems. This also underscores the confusion regarding institutional responsibility for the provision of services (public/private, local/national/international).' This statement rests on the often-repeated assumption in the international development literature that CBW-systems improve the communities' sense of ownership of problems and solutions. Our case study suggests that 'community ownership' could only be something that is indeed collective *as a community*. In our discussed cases, the three CBW systems have adopted different senses of community, often parallel to each other: the VHW are part of the political

community of Migule, the Wanawakes of a women's community, although a limited 'elite' version of female solidarity. The Kikumes are, more than anything, part of the community of PLHA. Their concerns and solidarity stretch beyond the geographical border of Migule, but do not necessarily reach the political community, or the female solidarity community. Thus, when commitment to a particular issue is needed, the geographical definition of community does not always include all persons registered in that community.

If 'ownership' is important to service delivery in a community, than it is probably wise to define community as a political entity. As the case study of care and prevention with regard to HIV/AIDS in Migule shows, service delivery of this kind would benefit from a comprehensive approach based on collaboration between the different institutions, including the CBWs. The CBWs in Migule work together, collaborate and sit in the different committees at community level. Still there is no coordination of activities. This can be explained by the individual dependency of each organisation and political entity. Better coordination and regulation of funds, conditions, legislation, and implementation would increase the possibilities for a holistic community approach to HIV/AIDS. This in turn, suggests the necessity for a return of the state.

Accountability

This case study confirms that the accountability of the CBWs is, at best, directed at the institutions that fund them. As we observed in the literature review: 'CBWs dependency on exogenous institutions makes them less accountable to the community, and more to these (often absent) institutions.' Being accountable to 'often absent institutions', which have not much notion of what happens at the grass roots, increases ambiguity about the nature and destiny of resources.

The conflict over WFP food, distributed by Wanawake, is a good example: as Bujra and Baileys and others have observed, 'the limited resources of the nation are mirrored in the limited income of would-be volunteers. […] the tension between volunteerism and personal financial need, as well as between personal commitment and inadequate organisational resources' (Bujra and Baileys 2000: 42) might just be a

breeding ground for opportunism and corruption.[50] The food support distributed by Wanawake and donated by WFP, was a target for conflict from the onset. The mutual accusations between members of Wanawake and Kikume concerning the appropriation of funds –and, from a wider perspective, of the possibility of access to resources- suggested a contested interpretation of who deserved what. Above all, the conflict, dragged on over several years and escalating during the fieldwork for this research, showed lack of accountability of the Wanawakes towards the beneficiaries. If there was any accountability, it was directed at the immediate formal institutions involved: the involved ward officers who were supposed to supervise the distributions. The Wanawake headquarters felt responsible toward WFP, but not necessarily towards the beneficiaries at the grass roots. The ward officers, in turn, accounted for the Wanawakes in Migule towards the Wanawakes at the district level. However, as discussed above, ward officials are not accountable to beneficiaries or NGOs, only to their political superiors. In the end, few people felt the need to act in a transparent and accountable manner towards the beneficiaries. This confirms our second assumption with regard to accountability, namely, that community accountability (often unregulated and undefined) does not lead naturally to more equitable and sustainable service delivery. Rather, 'community accountability' means that service delivery schemes are only part of the same old hierarchies that have not contributed to previous attempts at improved service delivery.

Professionalisation:

Working Paper 1 states that 'professionalisation might not only improve the quality of the services delivered, but could also encourage more independence of local CBW systems. Nevertheless, it is not clear to what extent a further professionalisation would contribute to CBWs effectiveness without undermining the advantages of community-based service delivery.' The case studies indicate that home-based care is only useful and concrete when treatments are available and CBWs are trained to administer those treatments. Medical care could be professionalized if and when

---

[50] Gruber (2005) observes that the material advantages that tip into a poverty-stricken community to support the community-based initiatives to fight HIV/AIDS, can in itself easily become a reason for conflict and increasing exclusion.

conditions are set in place (adequate training, resources, and institutional support). In neither of the studied CBW programmes in Migule this was the case.

The professionalisation of psychological support is also out of reach of the CBWs. There is no culture of mental healthcare, and the social stigma attached to HIV/AIDS is far too present at the local level to think about community-based psychological support. The necessary socio-emotional care is mainly down to family members and, increasingly, organisations of PLHA.

Nevertheless, all organisations counted on the support and expertise of the trained dispensary nurses. Several of these women were active members of Kikume or Wanawake, others supported the different CBWs when necessary. These were, indeed, the professionals who are formally trained to provide counselling and medicines. The nurses –and, in their own way, the doctors in Migule- are crucial to the limited medical support the community can offer PLHA. They can provide the care for which the knowledge and training is necessary that the CBWs said to miss. However, the health care personnel did not prove capable of sustaining a HBC programme because of the lack of time and salary. There is, thus, formally still a gap to be filled in between these professionals and the willing CBWs of the VHW system, the Wanawakes and the Kikume members.

Individuals, CBWs, and institutions

What does the above say about the interlinkages between individuals, CBWs, and institutions? The case study shows that individual position as member of a community partly determines and shapes community participation: an elite position generates responsibilities and expectations, a political track record as well. Professional concern is also associated with certain responsibilities towards the community: health care professionals do provide services on a voluntary basis, and sit in councils and committees. In addition, personal motivation is strongly tied to personal interests: regardless of whether these interests reflect material gain, status capital, professional interest, or political aspirations. Such interests are easily translated in solidarity, albeit perhaps a limited version.

In the case of the CBO of PLHA, individual participation has still another dimension: status capital or professional or political gain do not play a role. Material gain – especially to support orphan children-, the search for a viable future (a 'liveable life' Judith Butler would say (2004)) for their children, and the recuperation of a minimum of self-respect and desire to live such a precarious life seem to be central to their activism. The reality in which many PLHA find themselves after receiving the positive HIV test, is one of poverty, public ostracism, and physical deterioration. By organising activities to combat HIV/AIDS and the added social ills in their community, the Kikume members also actively resist the spiral of socio-economic downfall, moral rejection, and physical deterioration. Their determined and engaged activism, based on personal experience instead of external pressure, might just be the most constructive form of AIDS activism.

The relation between the CBWs and the community is defined by their interests in participating. The Wanawake women represent a certain elite within the community, and provide the social care associated with women's community engagement and charity. Their relationship with the beneficiaries is largely clientelist; groups of loyal recipients support the status capital of the main characters in the organisation. The Village Health Workers, in turn, are community workers tied to the political organisation of Tanzanian villages. They are members of the ever-dominant ruling party (CCM) and rotate community tasks within the local political hierarchy. They are, have been, or will be, elected members of the Village Council, Ward Committee, they are village elders and ten-cell leaders, members of school boards and elders of FBOs. They are known to the beneficiaries, but represent a certain political authority. The Kikume members represent, in the best of cases, the positive side of the disaster that is unfolding in Migule. They are seen as honest and courageous representatives who offer solidarity and wisdom. At the same time, they represent everything that most community-members deny, or blame on 'bad individuals'. As all leaders in Kikume are mothers and fathers with no history of street walking or high mobility such as sex workers and truckers, they show the villagers a mirror that they do not always want to see.

The relation between these community-based initiatives and their institutional surroundings are complex. In general, as table 2 indicates, formal institutional support

is minimal. Nevertheless, all CBOs are part of the complex, often poor, in some cases corrupt and almost always hierarchical, institutional arrangements. If we include legislation, religion, norms and values under the denominator 'institutional arrangements', then we see that the existing institutional arrangement in Tanzania, and in particular in Migule, are detrimental to the spread of HIV/AIDS and to the activities of those who intend to fight this.

From the case study we can derive various concrete points that need attention in the relation between the community-based initiatives and the linked institutions that they deal with. First, as table 2 shows, funds get often stuck at a national or regional level. This is the case in government institutions as well as non-governmental. Grass roots organisation being the last link in the institutional chain, they often loose out. Second, the institutions (national and international NGOs, FBO, Government institutions and committees) that CBOs rely on often change: the training schemes that the VHW undertook are a good example: they received different training from widely differing institutions over twenty years, but still feel inadequately trained. As international paradigms change, so does the available support. Grass roots organisations have little say in these shifts, but do have to comply to demands, norms, and expectations if they want continuous support.

The diversity of institutions is, in principle, not bad in itself. It means that different services and support regimes are offered, which might generate choice. However, in reality such diversity can generate rivalry among institutions and among recipient CBOs. Community-based coordinating bodies such as the Village or Ward Councils are weak in the face of those organisations which have the resources. As the structures of governance are hierarchical, top-down, and very politicised, this makes the state as coordinating body weak at both local and national levels. Nevertheless, without such a coordinating entity to oversee both regional, district, and community-based nongovernmental initiatives, these initiatives cannot provide services and/or support on an equal and sustainable basis.

5, overview of structures, processes, community initiatives and outcomes

Structures (or: macro level)	Processes (or meso level)	Community initiatives (or micro level)	Outcomes
Poverty	Sex work	Witch Doctors	Uncontrolled HIV/AIDS transmission
Environmental degradation	Illegal trading	Ambiguous and contradictory contribution of Churces/FBO	Increasing health problems
Gender inequality	High geographical mobility		Orphans & poor children further marginalised
	Women blamed for HIV and sought out for unsafe sex	Increasing responsibilities on CBOs + hope for external aid.	Sexual abuse
Sexual Taboos	Cultural dislocation of sexual message		Moral divide, stigma emphasised
		Some CBOs more successful then others	Health care facilities cannot keep up
Political status quo	Confusing messages about sexual morals and risks	Medical services marginal but improved with external aid.	Community responsibility polarised
International pressure	Lack of protective legislation or law enforcement	Local government does not prioritise AIDS.	Weakening of kinship ties due to stigma, blame, poverty, & conflict over external support
	Lack of political will to change		
	Police + political corruption		
	Increasing role and expectations of (inter)national NGOs		

Bibliography

Asia Pacific Network of People Living with HIV/AIDS APN+ (2004). 'Position Paper 2 GIPA.'

Baylies, C. L. and J. M. Bujra (2000). *Aids, sexuality and gender in Africa: collective strategies and struggles in Tanzania and Zambia*. London; New York, Routledge.

Boesten, J. (2005). 'Literature Review: Community-Based Workers and Service Delivery.' CDD Working Paper 1, Bradford Centre for international development.

Bujra, J., (2000). 'Target Practice: gender and generational struggles in AIDS prevention work in Lushoto. In: C. L. Baylies and J. M. Bujra eds. *Aids, sexuality and gender in Africa: collective strategies and struggles in Tanzania and Zambia*. London; New York, Routledge.

Bujra, J., and S. N. Mokake (2000). AIDS Activism in Dar es Salaam: many struggles; a single goal. In: C. L. Baylies and J. M. Bujra eds. *Aids, sexuality and gender in Africa: collective strategies and struggles in Tanzania and Zambia*. London; New York, Routledge.

Butler, Judith, (2004). *Undoing Gender.* Boca Raton, Routledge.

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

Global Movement (2005). 'Revitalising the global movement of people living with HIV/AIDS, a Think tank Meeting'. Nairobi, Kenya http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf. [accessed March 2006]

Green, M. (2006). 'After Ujamaa? Cultures of Governance and the Representation of Power in Post Socialist in Tanzania ' Paper presented at the Association of Social Anthropologists Annual Meetings, Manchester, July 2003.

Gysels, M., R. Pool, and B. Nnalusiba, (2002). 'Women who sell sex in a Ugandan trading Town: life stories, survival strategies and risk.' *Social Science and Medicine* 54: 179-192.

Haffajee, R. (2003). 'The women of Kiwakkuki: leaders in the fight against HIV/AIDS in Kilimanjaro, Tanzania.' www.pubpol.duke.edu [accessed February 2005]

Hanson, S. (2000). 'Health sector reform and STD/AIDS control in resource poor settings -the case of Tanzania.' *International Journal of Health Planning and Management* 15: 341-360.

Haram, L. (2005). 'AIDS and risk: The handling of uncertainty in northern Tanzania.' *Culture, Health and Sexuality* 7(1): 1-11.

ICRW. (2002). 'Understanding HIV-related Stigma and Resulting Discrimination in Sub-Saharan Africa.' www.icrw.org [accessed 20-05-2005].

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 (2000). Baseline Survey and community needs assessment for reproductive health services in the District. Migule Case Study.

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

Mfangavo, C., A. Toner, F. Cleaver, and J. Boesten, (2005). 'Policy Overview: A review of policy and practice in relation to water and HIV/AIDS in Tanzania'. CDD Working Paper 2, Bradford Centre for International development.

Mshana Gerry, M. L. P., Joyce Wamoyi, Zachayo S. Shigongo, David A. Ross, Daniel Wight, (2006). 'She was bewitched and caught an illness similar to AIDS': AIDS and sexually transmitted infection causation beliefs in rural northern Tanzania.' *Culture, Health & Sexuality* 8(1): 45-58.

Nnko, S., J.T. Boersma, M. Urassa, G. Mwaluko, and B. Zaba, (2004). 'Secretive females or swaggering males? An assessment of the quality of sexual partnership reporting in rural Tanzania.' *Social Science and Medicine* 59: 299-310.

Olenja, J. M. (1999). 'Assessing community attitude towards home-based care for people with AIDS in Kenya.' *Journal of Community Health* 24(30): 187-99.

Parikh, Shanti A. (2005). 'From auntie to disco: The bifurcation of risk and pleasure in sex education in Uganda', in Vincanne Adams and Stacy Leigh Pigg (eds.) *Sex in Development. Science, Sexuality, and Morality in Global Perspective.* Durham and London: Duke University Press, pp. 125-158.

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

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

Silberschmidt, M., and V. Rasch (2001). 'Adolescent girls, illegal abortions and 'sugar daddies' in Dar es Salaam: vulnerable victims and active agents.' *Social Science and Medicine* 52(12): 1815-1826.

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, Spinhuis.

Vavrus, F. (2003). *Desire and Decline: schooling amid crisis in Tanzania*. New York, Peter Lang.

Worlamyo Aheto, D., K. Prosper Gbesemete, (2005). 'Rural perspectives on HIV/AIDS prevention: a comparative study of Thailand and Ghana.' *Health Policy* 72: 25-40.