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This briefing paper summarizes the results of research carried out in Hedaru, intermittently carried out over two years, 2005-2007. The study was initiated under the auspices of Dr F. Cleaver at the Bradford Centre for International Development and financed by the UK Department for International Development, DfID.

The current study forms part of a larger research project: "AIDS Activism, Stigma, and Violence". This is a comparative research project based at the ICPS and runs from December 2006 until April 2009. This research is funded by the Economic and Social Research Council under the ESRC Non-Governmental Public Action Programme. For further information about the research and this briefing paper, contact: Jelke Boesten
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Community Response to AIDS: Who Participates?

Study of the response to HIV/AIDS in Hedaru, Tanzania

Policy documents and designs increasingly emphasise the importance of the involvement of communities in the response to HIV/AIDS in Sub Saharan Africa. However, little is known about how local communities actually deal with the epidemic. This research focused on the response to AIDS at community level by studying one particular town, Hedaru, between 2005 and 2007.

This briefing paper intends to provide a) information about Hedaru, b) the AIDS epidemic and the response to AIDS in Hedaru, c) the problems encountered in fighting AIDS at community level, and d) key points arisen from this research.

Hedaru is part of Same district, Kilimanjaro region, Tanzania. The town is located some 50 km south of Same on the road to Dar es Salaam. Today, Hedaru hosts 22,000 people, a growth of 12.6 % in five years due to migration and natural growth.

Since the mid-nineteenth century, Hedaru was known as a rural village. It received a boost after independence, when the main road between Arusha and Dar es Salaam was built. Since then, Hedaru saw a *rapid population growth* that diversified its tribal and religious make up. Today, Christian faiths and the Islamic community live peacefully side by side, as do a range of tribes. Hedaru still receives many migrants from more rural areas in search for better opportunities.

Hedaru is attractive as it is an *important market town* and hosts every Thursday traders from the neighbouring Masaai plains and the Pare Mountains. As many roadside towns located on international trading routes, Hedaru also provides rest and entertainment for passing traders and truck-drivers.

Service provision such as education, justice, and health care lags behind the population growth the town experiences. Although two secondary and seven primary schools exist, this hardly covers all children. Likewise the health sector: Hedaru has one government dispensary, which is currently being extended. Hopefully, the extension will bring more professional personnel and equipment.

This research looked at the involvement of *community-based organisations* in the response to HIV/AIDS in Hedaru. The main organisations studied were the local branch of *KIWAKKUKI*, a women's organisation fighting AIDS having its headquarters in Moshi, and *KIKUHE*, a self-organised group mainly consisting of people living with HIV. In addition, a range of other local CBOs participated in the research.

HIV/AIDS in Hedaru

Hedaru is a roadside town with a high risk of HIV infection via commercial sex activities. This includes a mobile population of young men and women, which certainly feeds into HIV transmission. *HIV is, however, not only transmitted among this mobile population, but is also present among and transmitted by the wider population of Hedaru.* Recognising the presence of HIV in the wider community is important for the effectiveness of any response to the disease.

Based on antenatal blood testing, in 2002 the National AIDS Control Programme (NACP) estimated 5.5 % HIV prevalence in Hedaru. A review of antenatal testing in 2006, shows a prevalence of 2.3 %. These low and even declining figures are strongly influenced by people's fear of testing in their home town, even among pregnant mothers. In 2007, an exercise with nine ten cell leaders in the centre of Hedaru town resulted in an estimate of 13.3 % HIV prevalence, with a similar (13.5%) number of people deceased of AIDS in the previous years. This number is also more in keeping with regional and district prevalence rate estimates of 7.3 % and 12.3 % respectively.

These important findings (see table below) show the urgent need for a comprehensive AIDS care and prevention policy, in order to make sure that:

- **those who are now HIV positive will live as long and healthily as possible,**
- **those who need palliative and medical care will receive it,**
- **everything possible is done to stop further infections, and**
- **affected people such as carers and orphans receive appropriate support.**

Total Population	PLHA	Orphans	Deceased
517	69	69	70
%	13.3	13.3	13.5

With gratitude for the collaboration of the following ten cell leaders: Hamadi Kiondo Mbwambo, Fredrick S. Msinga, Greyson Kigondi, Magreth Stribani, Nakijwa F. Zakayo, Dand Ali Mbwambo, Fadhili K. Ntere, Zaina Drigo, and Zaina Amini. Their collaboration took place in complete confidence and without the disclosure of names or the discussion of individuals.

Response to HIV/AIDS in Hedaru

Medical services

Hedaru has one government dispensary, staffed by one medical assistant and several trained nurses. In addition, at least two private dispensaries exist in Hedaru. The government dispensary has trained staff to carry out Voluntary Testing and Counselling (VCT), but not the equipment to do the actual testing. Therefore, the medical personnel use Diagnostic Counselling and Testing, which allows for symptomatic HIV recognition. Although VCT and antiretroviral treatment (ARV) are now made available for free, the residents of Hedaru have to travel 50 km to get access to these services in the district capital. Treatment for opportunistic infections is available in Hedaru's dispensaries. A Village Health Workers scheme to provide home based care is in place, although it suffers from a lack of resources, resulting in little consistency.

Role of community-based organisations

In the area of *care and prevention,* a wide range of community-based organisations operate, providing food support, orphan care, home based care, and (peer) education. Self-organised groups of people living with HIV (Kikuhe, Chawamsa), women's groups (Kiwakkuki), and several other groups are active. The umbrella organisation Uvivikukahe has 24 member organisations registered as working in the area of HIV in Hedaru. Although so much activity in the area of AIDS seems positive, it also shows the fragmentation of the response. Several organisations only exist in name; others are registered organisations but only work for the benefit of few. It is not always clear who does what and why, or what happens with received resources. This suggests a problem of *participation, accountability and transparency*.

Members of several organisations have completed courses in a variety of issues, including home based care. However, no formal system of home based care exists. In 2007, the national organisation Wamata set up an office in Hedaru, providing free medicines for opportunistic infections.

Orphans and elderly are supported by a variety of organisations, including the above mentioned. Many more orphans are cared for by their extended families. Based on information from neighbours and schools, the organisation Kikuhe estimates that Hedaru has at least *800 orphans* in need of support. The children in the picture are supported by Kikuhe.

Role of faith based organisations

Faith based organisations are traditionally very active in the area of care and support for the chronically ill. Most importantly, they provide mental support for those who feel desperate. In many cases, they also provide essential financial support for medical purposes. The existing Lutheran, SDA, Catholic and Muslim organisations in Hedaru work well together on these issues.

However, many faith based organisations deliver a different prevention message than required by the Tanzanian government. Many insist that condoms, widely recognised as an effective method to prevent HIV transmission, are not safe or morally correct. Unclear and often contradictory messages about HIV transmission and safe sexual relationships feed into stigmatisation.

Institutional structures to fight HIV/AIDS

The aid industry, national and international NGOs often based in Moshi, or Dar es Salaam, provides funding and training for community-based initiatives. As such, leaders in Hedaru have attended courses on, for example, family planning, home based care, leadership, coordination, nutrition, and prevention. Using such information to improve the local response to HIV is not easy. Often, trained leaders find themselves without a solid institutional basis or resources to actually use their skills. Training of professional medical staff and resource funding for implementation has proved more successful.

The Tanzanian government, supported by the donor community, has done an excellent job in rolling out ARV for the general population. Regional and District hospitals now have trained staff and sufficient medicines to test and treat all patients who need it for free. Insufficient testing on the part of the population as a result of fear and stigma hampers the programme. In addition, those who live far away from district hospitals and who are too poor to pay for transport costs, drop out of treatment programmes easily.

The Tanzanian National Multi-sectoral Strategic Framework for HIV/AIDS 2003-2007 stipulated setting up a range of councils and committees from regional level down to sub-village level to coordinate care and prevention in communities. In 2006, Hedaru organised their committees and initiated planning. These committees could provide a platform for discussion about the details of the local epidemic and a resource for improved coordination of activities.

Key constraints to the HIV Response

Lack of resources

As a market town, Hedaru attracts rural dwellers in search of better opportunities. However, many people are very poor, especially families with chronically ill members. People affected by HIV/AIDS (or other chronic illnesses) often see their household income decrease due to the costs of care and loss of labour. Many need economic support to feed themselves and their families, and to pay for medicines and transport. As HIV has affected not only individuals, but the whole town, together people struggle to provide for such basic needs. The lack of resources in general also constrains the consistent implementation of home based care, education, and prevention programmes. Although there is some funding for HIV/AIDS related projects, this is mostly insufficient and temporary, and thus unpredictable.

Fragmentation

The fragmentation of both external support and local community based organisations who receive this support means that local organisations compete over too few resources. This, in turn, leads to the fragmentation of resources them self. As a result, there is never enough money or materials to implement a strong programme. The negative side of competition also generate tensions between recipients, further crumbling the solidarity needed in order to organise an effective HIV response.

Fragmentation also refers to the different, often contradictory, messages about prevention of HIV transmission. Schools, Churches, Mosques, health care personnel, and community organisations do not always agree on how to prevent HIV transmission and what 'safe sex' entails. This stops the HIV prevention message becoming common knowledge among the population.

Stigma and self-stigma
HIV is a disease like other diseases, not a moral curse. However, HIV often becomes a moral curse because of the sexual nature of its transmission. People often feel ashamed and fearful when they are tested HIV positive, thinking family and friends might get angry and will not accept them anymore. As a result, HIV positive people often keep silent about their health status. Women are particularly blamed for transmitting HIV, an unfair assumption which makes their already difficult position even worse. Although fear for coming out as HIV positive is thus understandable, it is also very dangerous: silence and denial leads to more infections, while it reinforces stigma. Discrimination and disapproving behaviour towards HIV positive people can only be fought by working together to show that the battle can be won, as long as everyone participates.

Accountability and Transparency
Organisations fighting HIV/AIDS are not always accountable and transparent. Often, members of organisations do not know how funds are spent and beneficiaries of programmes do not know how they could be selected. Organisations and programmes need managing and leadership. Most programmes are managed by volunteering community members who want to contribute to the AIDS response. They receive little to no institutional support to manage their programmes and organisations**.**

What to do next?

Coordination: activities and programmes should be better coordinated and supervised. This can be done by a committee of stakeholders such as the new ward and village AIDS committees. Such committees need to take their job seriously and make a plan which involves all interested organisations and individuals in their response to HIV. Such a plan can integrate existing programmes, and fight the fragmentation that exists on different levels.

Leadership: committees and organisations depend on good management, and thus on solid leadership. Leaders should be examples to the community, behave sexually responsible, share their knowledge with others, support and inspire other potential leaders, and invite participation of members, beneficiaries, and the general population in programmes. Rotating or elected leadership could guarantee a democratic organisation.

Participation: In order for any HIV strategy to be effective, as many people as possible should be involved. HIV is not only the problem of those who are affected, but of all. In particular commercial enterprises such as guesthouses should be involved in the response, as should the police forces, regular visitors to, and residents in Hedaru.

Gender: The relationships between women and men are very important in addressing HIV/AIDS. Women and men have to work together to discuss their understandings of HIV prevention, without blaming one another for possible transmission. Both men and women need to know how to protect themselves and should always be allowed to do so.

Resources: Although the government has done an excellent job rolling out VCT and ARV, towns like Hedaru need their own ARV and VCT services. In order to ensure good medical care and ARV follow-up, an *institutionalised* and professionally *supervised* home based care system would have to complement the hospital based services. TACAIDS has promised to allocate funds to communities; these funds can give a strong impulse to better management of the epidemic. In addition, funding from NGOs and donors can support the Hedaru programme to fight AIDS.

Accountability: Where there is funding, there is trouble, especially when there is never enough. Therefore, accounts need to be well kept and recipients have to be transparent about how they spend funding. Government institutions as well as community based organisations should be able to show their accounts to anyone at any moment; in that way both donors and the general population will be inclined to continue their financial and moral support.