The response to HIV/AIDS in Conflict situations

a research study into Rwanda, Burundi and Eastern-DRC

Summary Report

(full report available on http://cerebellum.tiscaliweb.nl)
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Conclusions

HIV/AIDS is on most organisations' agendas, and all are in the process of doing 'something', ranging from a policy debate at headquarter level to the actual implementation of projects in the field. Some manage effective projects and others do less quality work, though there are so many actors, that it is impossible within the scope of this study to assess the quality of each individual project or organisation.

One can conclude however, that the response is scattered due to a critical lack of coordination between different actors. Most organisations do not know what others are doing, do not have access to each others' documents, and there is no structured mutual learning regarding successes and mistakes. What is more, most organisations do not learn from their own successes and mistakes, as they do not measure the impact of their work.
Consequently, one can conclude that there is a pressing need to set standards for performance, improve mechanisms for measuring impact and quality, and to create systems for sharing information, which will enhance transparency and accountability.

The first objective of this study was "to identify the reasons for the inadequate response to HIV/AIDS in emergency settings in the Great Lakes Region".
The author has her doubts whether one can call the response to HIV/AIDS in this region 'inadequate', and would rather call it 'slow and uncoordinated'. In all three countries multisectoral national AIDS strategies have been designed recently, though these processes take time and implementation is on its way. Furthermore one can see a tremendous amount of local initiatives for both prevention and care in all three countries. A lot has been written on HIV/AIDS in complex emergencies, and many international organisations are looking at means to incorporate considerations of HIV/AIDS in their programmes, though these processes too are slow, and often hampered by bureaucratic structures and organisational agendas.

To be able to assess the quality of the response to HIV/AIDS in each of these countries, one should first get a more completed picture of all the actors. This study provides the first step to assemble a wide variety of data on organisations, projects, policies and guidelines, but is by no means complete. In order to obtain more comprehensive data for each country, that enable the planning of a joint response which looks at the added value of each organisation and distributes funds accordingly, organisations should start with being transparent about what they do, show what impact their efforts have, and reveal what it costs them to obtain those results.

The second objective was "to identify strategies for increasing resources made available for HIV/AIDS programmes in emergency settings". In the countries studied, resources have been increased considerably during the last year, and a more appropriate task would be to identify means to use these funds in a more effective way.
Though budgets for humanitarian aid have increased significantly over the last years, they are still subject to the political views of the donor in respect to the conflicting parties, thus funds are disbursed in an ad-hoc fashion, with short-term commitments, over-funding of certain programmes, and under-funding of others. There is very little coordination amongst different donors, and nobody has the overall picture of who is funding what, and how much money is being spent in total. Furthermore, the mechanisms for funding are unclear. Governments, international financial institutions, foundations and private institutions all have different means of disbursing their funds: Some provide funds to the government, or directly to the national AIDS programme; Some fund various UN-agencies, who do not implement projects, but act as intermediaries for projects by local or international NGOs; Some fund international NGOs who either pass on the money to local NGOs, or implement projects; Some only fund implementing agencies, or choose to implement projects themselves; and others use a mixture of all these funding mechanisms.
Donors should increase their transparency of funding. For a better response it needs to be clear which donors are funding which organisations, which amounts of funds are available for which types of interventions, and how different funds can be accessed by whom.

Within a complex emergency, with millions of displaced people who suffer recurrent epidemics of meningitis, malaria and other infectious diseases, who face problems of access to food, clean water and healthcare, and who are subject to constant outbreaks of violence, one can only assess the response to HIV/AIDS within the larger context of the humanitarian response.

Over the last decade the very nature of emergencies and humanitarian action has changed. Emergencies are protracted over long periods of time with countries in chronic or recurrent conflict, and humanitarian organisations have increased tremendously in number and size. Competition is fierce, and the quest for funds is sometimes more related to the existence of the organisation than to the humanitarian needs.

There has been much debate and criticism* of both humanitarian organisations and international donors in their response to complex emergencies, and this criticism is no different for organisations or donors responding to HIV/AIDS in these emergencies.

Issues of accountability dominate in all these discussions, and though implementing agencies are increasingly held accountable towards their donors, no mechanisms exist for accountability of either the donors or the implementing agencies towards the populations they serve. Children, young people, and people infected or affected by HIV/AIDS have rights and cannot be treated as mere objects of charity. Involving them in the planning of projects is not an easy task during an emergency, though with the existence of so many local associations, it is not an impossible undertaking, and more efforts should be made to provide support to organisations which are well rooted in the community. Moreover, accountability is based on evidence, and an increasing effort should be made to collect data before, during and after interventions to show not only the successes, but also to be able to learn from mistakes.
The first step to accountability is transparency. Only by making information available to the scrutiny of the public, can populations participate in debates on by whom and how they are best served.

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* The following articles can be downloaded from the web-report on:
http://cerebellum.tiscaliweb.nl/my_project/funding.htm

- The 'bilateralisation' of humanitarian response: A background paper for UNHCR, Joanna Macrae, HPG HUMANITARIAN POLICYGROUP, October 2002
- A NEW LOOK AT CIVIL SOCIETY SUPPORT IN RWANDA, Sue Unsworth and Peter Uvin, Commissioned by DFID, October 7, 2002
- War and Accountability, ICRC, FORUM, April 2002
- Humanitarian assistance: Breaking the waves of complex political emergencies. A literature survey, Centre for Development Research Copenhagen
- Towards good donorship: the changing role of official donors: HPG HUMANITARIAN POLICYGROUP October 2002
- The Cartel of Good Intentions; William Easterly in Foreign Policy, July/August 2002

Recommendations

1. **Standards for quality and minimum requirements need to be made for the response to HIV/AIDS;**
   Though guidelines and toolkits exist, standards which appeal to the professionalism and values of organisations should be made. The Inter Agency Standing Committee Reference Group on HIV/AIDS in Emergency Settings is preparing a matrix to provide guidance on HIV/AIDS actions to be implemented in different phases of a humanitarian crisis, and is revising the 1996 guidelines of UNHCR, WHO and UNAIDS on HIV/AIDS in emergency settings. In addition, the Sphere Project, which provides minimum standards and key indicators for disaster assistance in five sectors, is adding a chapter on HIV/AIDS in its current revision.

   ⇨ It is recommended that both institutions make clear what the *minimum* requirements are in the response to HIV/AIDS, as well as the *recommended* requirements.

2. **Mechanisms to measure performance, quality and impact need to be incorporated into the planning stage of projects;**
   Most projects start without baseline data. Needs assessments, vulnerability analyses, and behavioural studies are often done halfway through a project, without using the results to modify strategies. Proposals often do not set clear measurable objectives: A lot of jargon is used, while terms like: to "raise awareness", "change behaviour", and "reduce vulnerability" only have a meaning when they are accompanied by measurable indicators. There is often NO monitoring during the project which can lead to adjustments in strategies. Evaluations are usually done by external consultants or separate Monitoring and Evaluation departments at the end of a project, and are not sufficiently used in the planning of a new cycle.

   ⇨ It is recommended that mechanisms for Monitoring and Evaluation are incorporated into the planning stage of a project, and as such form a prerequisite for approval of a proposal. Indicators should be linked to the minimum or recommended standards of quality as mentioned above.

3. **There is a need to improve accountability towards beneficiaries;**
   Children, young people, and people infected or affected by HIV/AIDS have rights and cannot be treated as mere objects of charity. In recent years donors have increasingly scrutinised the actions of implementing organisations. The need for the control over resources has reached a degree that for each large funding source a new coordination mechanism is established (e.g. in Rwanda there are separate coordinating bodies for the WorldBank MAP funds, the Global Fund, the SIPAA funds, and UN funds, which exist alongside the National AIDS Programme). Implementing agencies are increasingly held accountable towards their donors, though no mechanisms exist for accountability of either the donors or the implementing agencies towards the populations they serve.

   ⇨ It is recommended that a genuine dialogue is held with beneficiaries of humanitarian aid, that they are involved in the planning stages of projects, and that they receive reports which demonstrate the quality and impact of interventions.

4. **All stakeholders should have improved access to information;**
   Information that can lead to improve 1. the quality of the response (by providing guidelines, toolkits, manuals), 2. the coordination of the response (by showing who does what), and 3. access to funds (by showing which donors will fund what), should be readily available to all stakeholders in the country.

   ⇨ It is recommended that 'Information Centres', or Approaches for 'Field-Based Information Management' are established for each country.

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Introduction

Save the Children UK has been commissioned by UNICEF and UNAIDS to do research in Rwanda, Burundi and Eastern DRC, to describe humanitarian organisations' response to HIV/AIDS in emergency settings. Several months were spent in 2002 interviewing representatives of key organisations, visiting projects and collecting studies, proposals and reports. An internet search was done for each organisation's policies, strategies, best practices, guidelines, manuals and toolkits. The detailed recollection of data can be found in the full report, which is available on CD and published temporarily on the author's website: http://cerebellum.tiscaliweb.nl/my_project/First_Page.htm.

While this summary report focuses on key findings and next steps, the full report is built up in three parts:

- **The Problem:** The first part describes why the risk of HIV/AIDS transmission is high in conflict, what has been written about HIV/AIDS in emergencies, and what the response ought to be in terms of prevention, diagnosis, care & support, and impact mitigation. This section also gives a brief description of what is being done in these terms in the countries visited, and concludes that there is a need for more emphasis on diagnosis, care & support, and impact mitigation to obtain a comprehensive response
  ⇨ http://cerebellum.tiscaliweb.nl/my_project/default_problem.htm

- **The Great Lakes:** The second part describes who is doing what in Rwanda, Burundi and Eastern DRC, and consists of an extensive framework linking to project descriptions, interview-notes, websites of organisations and donors, and contact details of country programmes. In this part one can find a large array of guidelines and toolkits made by different organisations.
  ⇨ http://cerebellum.tiscaliweb.nl/my_project/default_Great_Lakes.htm

- **Stakeholders:** The third part gives a description of various stakeholders, describes their present role, and points at various obstacles in obtaining an adequate response to HIV/AIDS in emergency settings (coordination and planning). This section has a few pages on funding mechanisms and links to several articles that discuss the changing role of donors in humanitarian aid.
  ⇨ http://cerebellum.tiscaliweb.nl/my_project/default_Stakeholders.htm

Background

Why was this research proposed?

Research has showed that the humanitarian response to a rapidly growing HIV problem in conflict countries was grossly inadequate[1].
The Inter-Agency Task Team on HIV/AIDS and Children Affected by Armed Conflict in August 2001 recommended that a study be carried out as to why the current response is inadequate, with a specific focus on the Great Lakes region, where conflict and HIV overlap significantly. It was requested that such a study be followed up by a capacity building process of humanitarian staff in the region. An agreement was made that UNAIDS would fund the work through UNICEF, who contracted Save the Children UK to implement the research.

[1] UNICEF. HIV/AIDS and children affected by armed conflict. Tamar Renaud, April 2001 and Save the Children HIV and conflict: A double emergency 'Without war, we could fight AIDS'. Andrew Lawley and Douglas Webb, 2002

What did the research aim to achieve?

1. To identify the reasons for the inadequate response to HIV/AIDS in emergency settings in the Great Lakes Region;
2. To identify strategies for increasing resources made available for HIV/AIDS programmes in emergency settings;
3. To build humanitarian organisations' capacity to respond to HIV/AIDS in emergency settings.

How did it aim to achieve this?

The designed process was to 1. Conduct a literature review of existing research available in the Great Lakes Region, 2. Interview key donors involved in supporting humanitarian agencies during emergencies so as to identify funding priorities in emergency settings, and 3. To design and implement three short training courses, in close cooperation with UNICEF, (and in conjunction with UNAIDS) based on the study findings, for key agency personnel (UN/NGO/Government) in Kigali, Bujumbura and Goma.

Methodology

Visits were made to Kigali and Ruhengeri in Rwanda, Goma and Bukavu in Eastern DRC, and Bujumbura and Gitega in Burundi. In total ninety-one interviews were conducted with representatives of various government bodies, national and international organisations, and donors, which included programme directors, project managers, HIV/AIDS advisors, project staff, health professionals, school teachers, and 'peer-educators'. A full account of the interviews can be found in the web based report in the 'Great Lakes section'.
Publications, reports and other documents were collected and copied where possible from different organizations, and an internet search was done for each organisation's policies, strategies, best practices, guidelines, manuals and toolkits.

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Findings

Background to the conflict

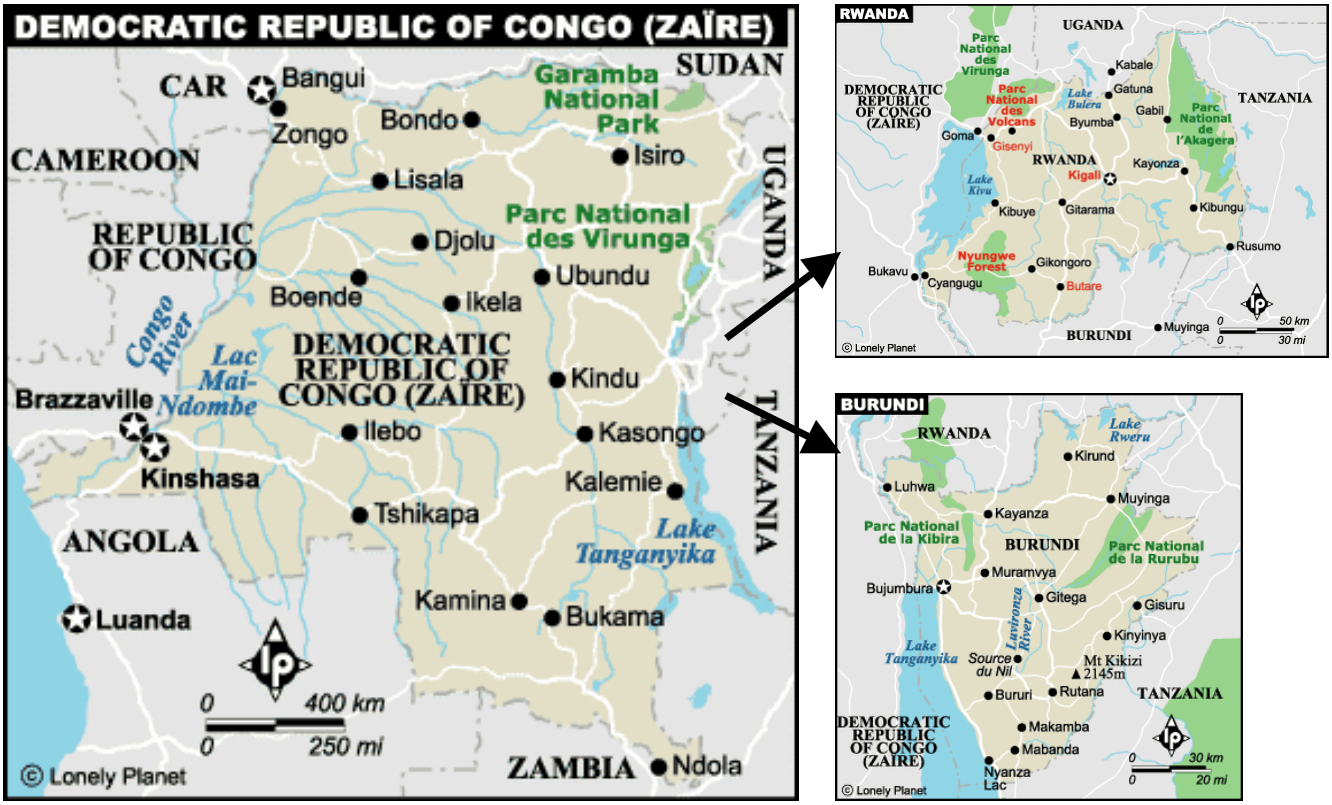
THE GREAT LAKES REGION CONFLICTS[2]

Eight years after the genocide in Rwanda, the Great Lakes Region is still afflicted by ongoing wars in Burundi and the Democratic Republic of Congo (DRC).
Central to the conflict in the region, is the war in DRC, involving at its height six external state armies, various factions rebelling against the Government, as well as other armed non-state actors, using the country as a haven from which to pursue their own interests.
In Burundi a political agreement was finally signed on the transitional government. The armed rebellion, however, has yet to commit to the peace process and current fighting on the ground continues and may intensify. Rwanda repelled incursions from rebel forces into the Northwest in May and June, but has expressed serious concern about the alleged massing of rebel forces in the Kivus.

[2] The text was taken and modified from: OFFICE FOR THE COORDINATION OF HUMANITARIAN AFFAIRS (OCHA) Humanitarian Briefing Packs of Burundi (April 2002) and Democratic Republic of Congo (May 2002) http://www.reliefweb.int/library/profiles/; Maps are from Lonely Planet http://www.lonelyplanet.com

Some 1,130,000 people from the region are refugees, and a further 3,013,000 are displaced within their own countries. But it is not only these populations who are at risk: host communities face additional demands on their own meagre resources, livelihoods are threatened by insecurity, and access to the most basic of social services – health and education – is limited.

The civil war in Burundi has already eroded the social and economic infrastructure. The combination of drought and insecurity has affected crop yields and the ability to harvest, while malaria, cholera and measles epidemics have ravaged the population.
Access to populations in need continues to be extremely difficult, hampered not only by sporadic and unpredictable insecurity, but also affected by direct attacks upon humanitarian personnel and operations.



Epidemiological data

UNAIDS, UNICEF and WHO have made epidemiological fact sheets which have been recently up-dated. New reports were published in July 2002, and are available on http://www.whobarcelona.info/AIDS2002/ and on the UNAIDS site http://www.unaids.org.

The data from the July 2002 fact sheets of Burundi, Rwanda and DRC have been compiled in Table 1. on the next page. Much of the data is missing and caution must be used in interpreting any figures which are available. It should be noted that in the countries a lot of these 'missing data' are available, though simply need to be gathered in a central point where they can be processed and made available to others.

Data on who are most affected and who are most vulnerable are not available.
The popular perception in rural areas is that 'the destitute', and 'the promiscuous' are most vulnerable. Many people referred to the lack of food which increases vulnerability. *"When a woman does not have enough to feed her children she will find a man to feed them"* (though this does not necessarily make her a prostitute or commercial sex worker). Many talked about

the vicious cycle of the lack food which renders you more vulnerable to disease, and disease which prevents you from earning money and buying food. This sounds very plausible, however, representatives of international organisations still claim that commercial sex workers, soldiers and truck drivers are most vulnerable. There are no data to substantiate this, and one should be careful with this kind of stereotyping as it causes stigma and might influence the risk-perception of those who do not consider themselves belonging to such a group[*].

Table 1. Data compiled from UNAIDS/UNICEF/WHO Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. Update 2002

	Burundi	Rwanda	DRC
Population	6,502,000	7,949,000	52,522,000
Adults and children living with HIV	390,000	500,000	1,300,000
Adult rate	8.3%	8.9%	4.9%
Adults (15-49) living with HIV	330,000	430,000	1,100,000
Women (15-49) living with HIV	190,000	250,000	670,000
Children (0-15) living with HIV	55,000	65,000	170,000
Deaths in 2001 due to AIDS	40,000	49,000	120,000
Current living orphans	240,000	260,000	930,000
HIV sentinel surveillance	latest 1998: for pregnant women only urban:18.5% rural: 19.7%	latest 2000: for urban pregnant women only: 23%; For STI 1996: urban 41.8% and rural 27.8%	latest 1999: for pregnant women only: urban:4.1 % rural:8.5% For STI 1998: rural 99.9% (??) For sex workers 1997: 29%
Reported AIDS cases	latest 1998: one table mentions 581 new cases, another 514	**not available**	latest 1998: one table mentions 3503 new cases, another 1263
Curable STIs	**not available**	**not available**	**not available**
Estimated size of populations at increased risk of HIV infection	**not available**	**not available**	**not available**
Health Service and Care indicators:			
% of population with access to health services (total)	**not available**	**not available**	**not available**
Contraceptive prevalence rate (%)	9 (1990-1999)	21.2 (1992)	8 (1990 - 1999)
Percentage of contraceptive users using condom	**not available**	**not available**	**not available**
% of births attended by skilled health personnel	24.9 (2000)	30.8 (2000)	69.7 (1999)
% of ANC clinics where HIV testing is available	**not available**	**not available**	**not available**
% of PLWHA who have access to ARV	**not available**	**not available**	**not available**
Number of PLWHA receiving HAART	**not available**	**not available**	**not available**
Coverage of VCT	**not available**	**not available**	**not available**
Knowledge and Behaviour	**not available**	**not available**	**not available**
Prevention Indicators:			
Condom availability nationwide	**not available**	**not available**	**not available**
PMTCT nationwide	**not available**	**not available**	**not available**
Screening of blood transfusions nationwide	**Not available**	**not available**	**not available**

[*] De Cock et al in *Lancet* 2002; 360: 67-72 argue that: "Approaches to the prevention and control of the HIV/AIDS epidemic in Africa have been heavily based on early experiences and policies from industrialised countries, where the disease affects specific risk groups". and "With the exception of the Caribbean, only in Africa is the epidemic generalised rather than concentrated in and around specific risk groups, with almost the same number of women affected as men".

Stakeholders

In the Great Lakes region there are very many different actors, including a huge variety of both local and international organisations, UN-agencies, government bodies, and donors. The overall response is scattered, when looking at the whole spectrum of HIV/AIDS prevention, diagnosis, care & support, and impact mitigation. In one place you can have one organisation doing voluntary counselling and testing (VCT), various organisations doing information education and communication (IEC), an organisation distributing condoms, another that does treatment of sexually transmitted infections (STIs), one or two that care for orphans, one that gives psycho-social support to PLWHA, and one that supports prevention of mother to child transmission (PMTCT). Coverage of programmes is patchy at best and coordination between the implementing agencies is such that a comprehensive response is not being realised. In general terms, large international organisations have engaged mostly in projects for HIV prevention, and that care and support for those affected is provided predominantly by smaller, local organisations.

This section looks at the different actors in the humanitarian response, which include international donors, international organisations, government bodies, and national organisations.

International donors

Who are presently funding projects related to HIV/AIDS in the Great Lakes Region?

- ⇨ **Governments:** bilateral aid and project-based aid:
  The United States Agency for International Development (USAID), the Department for International Development of the British government (DFID), The Netherlands development Cooperation, Swedish International Development Assistance (SIDA), Norwegian development assistance, Deutsche Gezellschaft für Technische Zusammenarbeit (GTZ), Coopération Française, Coopération Belge, Luxembourg development assistance, Irish development assistance, Italian development assistance, Swiss development assistance, Canadian International Development Agency (CIDA), Japan's Ministry of Foreign Affairs (MOFA).
- ⇨ **European Union:** development funds (Europe-Aid) and HIV/AIDS funds. [No emergency funds (ECHO) as to date]
- ⇨ **WorldBank:** Multi-country AIDS Programme (MAP) loans, MAP2 grants, post-conflict facility grants.
- ⇨ **The Global Fund** to Fight AIDS, Tuberculosis and Malaria.
- ⇨ **Private Initiatives:** the Bill and Melinda Gates Fund, the Soros Foundation, the Ted Turner Foundation, the Ritch Fund, Kreditanstalt Fur Wiederaufbau, Surf Survivors fund UK, Posnansky UK, and various religious foundations.

Issues mentioned that contribute to a slow and uncoordinated response to HIV/AIDS:

- There is a big difference in funding mechanisms, and a large variation in the degree to which donors want to have control over the content of programmes and projects. Some donors have technical departments which specialise in HIV/AIDS, and finance projects according to their own policies.
- There is little co-ordination among donors: most are not aware of all other donors in the same country, which leads to overlap.
- There is a tendency to fund many small projects, or parts of projects for short periods, which leads to scattered projects with many actors all doing little things without anyone being accountable.
- Though budgets for humanitarian aid have increased significantly over the last years, they are still subject to the political views of the donor in respect to the conflicting parties, and funds are disbursed in an ad-hoc fashion, with short-term commitments, over-funding of

certain programmes and crises, and under-funding of others, and very little coordination amongst different donors**
- Funding cycles differ for every donor, which makes planning complicated for recipients.
- Many donors cannot fund local organisations, but have to route their funds through international organisations: Sometimes the added value of this intermediary is not clear, though it absorbs a large part of the funds for running costs.
- Application procedures differ a lot, and it is often difficult for organisations to know how to access funds (this problem is seen more with local organisations than with international organisations, who have fundraising departments). Formats for proposals are often very cumbersome and too detailed, and funding depends a lot on personal contacts. In addition, it should be mentioned that those that have the best writing skills for proposals and reports, may not necessarily be the ones with the best projects.
- Some donors do not want NGOs to depend completely on their funds and will only grant co-financing schemes: NGOs end up having many different donors for one project, which means many different proposals, narrative reports and financial reports, taking time away from programme implementation.

** One of the differences between humanitarian assistance and development aid is that the latter is increasingly based on 'good governance', i.e. governments that have made Policy Reduction Strategy Papers, Financial Information Management System reports, a Report on Observance of Standards and Codes, a Medium Term Expenditure Framework, and a Debt Sustainability Analysis for the Enhanced Heavily Indebted Poor Countries Initiative. Humanitarian assistance does not require such extensive scrutiny, and depends on the political inclination of the donor of that moment in time.

International Organisations

Which organisations are active in HIV/AIDS in the Great Lakes Region?
(NB. The list is not exhaustive)

- ⇨ **United Nations:** Joint United Nations Programme on AIDS (UNAIDS), United Nations High Commission for Refugees (UNHCR), United Nations Children's Fund (UNICEF), World Health Organisation (WHO), United Nations Population Fund (UNFPA), United Nations Development Programme (UNDP), World Food Programme (WFP), United Nations Educational, Scientific and Cultural Organization (UNESCO), International Labour Organisation (ILO), International Office for Migration (IOM), Food and Agriculture Organization of the United Nations (FAO), United Nations Development Fund for Women (UNIFEM), United Nations Economic Commission for Africa (ECA)
- ⇨ **International NGOs:** Actionaid, Agency for Co-operation and Research in Development (ACORD), African Humanitarian Action (AHA), American Refugee Commission (ARC), CARE (UK, US, International), Concern, Cordaid, German Development Group (DDG), Family Health International (FHI), Handicap International (France and Belgium), International Planned Parenthood Federation (IPPF), International Rescue Committee (IRC), Oxfam (UK and Quebec), Médecins Sans Frontières (MSF-Belgium, Holland and France), Norwegian People's Aid (NPA), Population Services International (PSI), Save the Children Fund (SCF-UK and US), Women and Rural Development Network, ZOA Refugee Care, and others
- ⇨ **Academic institutions:** Harvard University, Institute of Research for Peace, Johns Hopkins University, Centre for Disease Control (CDC).
- ⇨ **Red Cross:** the International Committee of the Red Cross (ICRC), International Federation of Red Cross and Red Crescent Societies (IFRC), National Red Cross Societies of Sweden, Belgium, Norway, the Netherlands, the US, the UK and others.
- ⇨ **Faith Based Organisations:**
  Anglican Church, Adventist Development and Relief Agency (ADRA), Caritas, Catholic Relief Services (CRS), Christian Aid, Aga Khan, Africare, AMUR, Compassion International, Evangelical Church Association, Evangelical friends pacifist church, Futures Group International Foundation, Tear fund, Trócaire, Norwegian Church Aid, Lutheran World Federation, Jesuit Refugee Services (JRS), Upstream Christian Initiative, World Vision, and others.

The list is not exhaustive and there is a big difference between all organisations, which makes it impossible to note down all issues mentioned without generalising them. When looking at the "traditional humanitarian organisations" (i.e. the international NGOs Red Cross, and UN agencies that tend to provide humanitarian assistance -or emergency relief- at the very onset of a complex emergency), there is no common denominator to be found either. For example MSF-Holland has an HIV/AIDS project in Bukavu, but does not incorporate HIV/AIDS in their projects in the rest of the DRC or Burundi; WFP provides food for organisations that support people infected or affected by HIV/AIDS in Rwanda, though has no mention of HIV/AIDS in any of its documents in E-DRC; UNICEF is incorporating considerations of HIV/AIDS into all their programmes in Rwanda and Burundi, though not in E-DRC. The ICRC has a project for HIV/AIDS in prisons in Burundi, though in Bukavu they say HIV/AIDS does not fall within their mandate. The Great Lakes pages[3] in the full report give a detailed description of various organisations.

Issues mentioned that contribute to a slow and uncoordinated response to HIV/AIDS:

- Many organisations tend to have their own 'agendas', though it is usually not clear to others which main points these contain
- Many organisations function as donor and as implementing agency at the same time, i.e. they implement their own projects while at the same time they serve as a donor for other organisations
- Coordination among organisations is often limited to the non-implementing organisations in the capital city
- There is a lot of competition for funds, which causes a reluctance to share information
- There is a competition for personnel, in the sense that staff trained by one organisation are often hired by another organisation at a better salary
- Some organisations are perceived by others as good, others as bad, without explicit criteria for measuring performance or impact.

Government

Who is active in HIV/AIDS within the government?

The Commission Nationale de Lutte contre le SIDA (CNLS), the Commission Provinciale de Lutte contre le SIDA (CPLS), the Treatment and Research on AIDS Centre (TRAC), the Programme Nationale de Lutte contre le SIDA (PNLS), Protection and Care of Families Against HIV/AIDS (PACFA) the Project of the First Lady of Rwanda, Mrs. Jeannette Kagame, the Great Lakes Initiative on AIDS, health centres, hospitals, laboratories, schools, the Ministry of Defence, the Armed Forces, the Ministry of Education, the Ministry of Health, the Ministry of Local Administration and Social Affairs (MINALOC), and the Ministry of youth, sports and culture.

The CNLS in Rwanda, Burundi and DRC have been founded in 2001-2002. Their structure is roughly the same in all three countries, with a multi-sectoral body which includes different ministries and falls directly under the presidency at capital level, and a decentralised system with committees at provincial and district level. The national plans are well elaborated and give a good picture of what needs to be done in the country.

[3] http://cerebellum.tiscaliweb.nl/my_project/default_great_lakes.htm

Issues mentioned that contribute to a slow and uncoordinated response to HIV/AIDS:

- Though the systems are in place, at the time of the visits they were not yet resourced (WorldBank loans were signed for Burundi and Rwanda in August and September of 2002); At a national level they have just taken up office, but do not yet have proper communication and information systems, transport, and other logistics and administrative systems to run a national programme properly.
- Decentralisation has been planned, and committees have been installed in provinces, though they have not yet received any funds to work with. In general one can say that the provincial committees are very competent, but the capacity at district level varies a lot. In Eastern DRC there is a coordinator at provincial level, though no multisectoral committee.
- Many people who were trained to work within the national AIDS programme at a decentralised level, now work for international organisations.
- The national plans have been written in a joint- and coordinated effort with other stakeholders (UN-Theme group, some donors, and a few INGOs), though when finished all actors committed only to scattered bits of funding (a VCT project here, PMTCT there, IEC elsewhere, etc.)
- All government institutions (health centres, schools, VCT centres etc.) are dependent on international organisations for funds until the WorldBank MAP loans come to effect.

National Organisations

Which are the local organisations working within the field of HIV/AIDS in the Great Lakes Region?

Very many small associations exist throughout the Great Lakes Region, and many collective organisations are formed to represent a number of associations in one district or province. Their activities vary a lot; some provide support to PLWHA, others work together with the health system to provide basic services (STI treatment, VCT etc), some care for orphans, and others look at human rights issues and discrimination.

Association d'aide aux victimes du SIDA (AVISI), Appui aux orphelins du SIDA et aux personnes infectées par le VIH (APOPI), PRAUTAO, Solidarités paysannes, Association nationale de soutien aux séropositifs et sidéens (ANSS), Cellule de lutte contre le SIDA/ Association des Guides du Burundi (AGB), Association pour recoudre le tissu social (ARTS), Association burundaise pour le Bien être familial (ABUBEF), Association des donneurs volontaires de sang (DVS), Centre d'étude et de sensibilisation pour l'action sociale au Burundi (CESAB), Association « Il est vivant », Alliance burundaise contre le SIDA (ABS), MENYA-MEDIA, Famille pour vaincre le SIDA (FVS), Collectif pour la promotion des associations des jeunes (CPAJ), Association des scouts du Burundi (ASB), Mutualité d'espoir et soutien des personnes atteintes du SIDA (MESPS), Association des jeunes unis contre le SIDA (AJS), Good generation of Burundi (GGB), Association Turwanye ubukene, Nouvelle Espérance, Solidarité-Renaissance -Fraternité (SRF), Association d'encadrement des jeunes inoccupés par les activités ménagères (EJIAM), Infirmiers sans frontière (ISF), Foyer islamique de la charité (FIC), Centre mobile des soins et assistance à domicile des malades du SIDA (SADOMS), Rassemblement des jeunes contre le SIDA (RJSI), Programme des jeunes non scolarisés et déscolarisés (PJSD), Association de prise en charge des orphelins du SIDA (APECOS), AFOPROCA, Force universitaire contre le SIDA (FUS), Jeunesse solidaire et responsable (JSR), Association pour l'assistance aux Déshérités (AAD), Centre de recherche et de promotion de la médecine traditionnelle (CERPROMET) , Assistance aux malades du SIDA (ASM) , Solidarité pour le redressement des toxicomanes (SORETO), Action contre le SIDA au Burundi (ACSB), Association GIRIMPUHWE, Association des Transporteurs (ATRABU), Solidarité pour les orphelins du Burundi (SOB), CEPBU, Croix Rouge du Burundi (CRB) , Xaveri Burundi, Action chrétienne auprès des PVVS (ACVS), Eglise Episcopale - Diocèse de Bujumbura (EEDB), Bureau national de l'enseignement catholique (BNEC), Communauté Islamique du Burundi (COMIBU : Commission de lutte contre le sida), Trauma Healing Centre, Eglise des Amis du Burundi, Association des tradi-praticiens du Burundi (ATRAPRABU), Appui Psychosocial des Victimes du Sida (A.P.V.S.), Association de Lutte contre la Pauvreté (ALP), Fondation pour l'Enfance au Burundi (FEB), Appui aux Personnes Atteintes du Sida (APAS), FASHA, Prevention Group,

Association Nationale des Séropositifs (ANSP), Association Rwandaise de Bien Etre Familiale (ARBEF), Arbre de Vie, ATRACO, Association des Veuves de Génocide (AVEGA), Society for Women and AIDS in Africa Rwanda (SWAAR), Society for Women and AIDS in Africa Burundi (SWAA-Burundi), Centre Nationale des Jeunes Chrétiens (CNJR), Friendship peace house, RCCTC, Rwanda Women's Network, Crois Rouge Rwandaise, SNDV, PRAUTAO, Association Nationale de Séropositifs et Sidéens (ANSS), Bureau pour le Volontariat au service de l'Enfance et de la Santé (BVES), Action et Concertations pour la lutte contre le SIDA – Plate Forme du Nord Kivu (ACOLSI-PNK), Fondation Femmes Plus (FFP), Action des Femmes pour le Développement Intégral (AFEDI), Choisir la vie, AMADI, Forum d'assistance aux Orphelins, aux victimes du SIDA & aux Séropositifs (FORSE), Réseau National Ethique, Droit et VIH (REDS), PAMI, Fédération de Scouts Congolais (FESCO), Ligue des jeunes contre le SIDA and many many others.

Issues mentioned that contribute to a slow and uncoordinated response to HIV/AIDS:

- Many organisations have good programmes, which are well rooted in the community, but they have no funds.
- Most organisations depend on donations from International NGOs and UN-agencies which are present in the country, and have no direct link with institutional donors.
- Though many international organisations mention 'partnerships' with local organisations in their reports, these 'partnerships' often consist of ad-hoc donations; i.e. a few hundred dollars for a workshop here, for a training session there, some petrol now and then, some money to print a leaflet, etc., but no structured support with an annual plan.

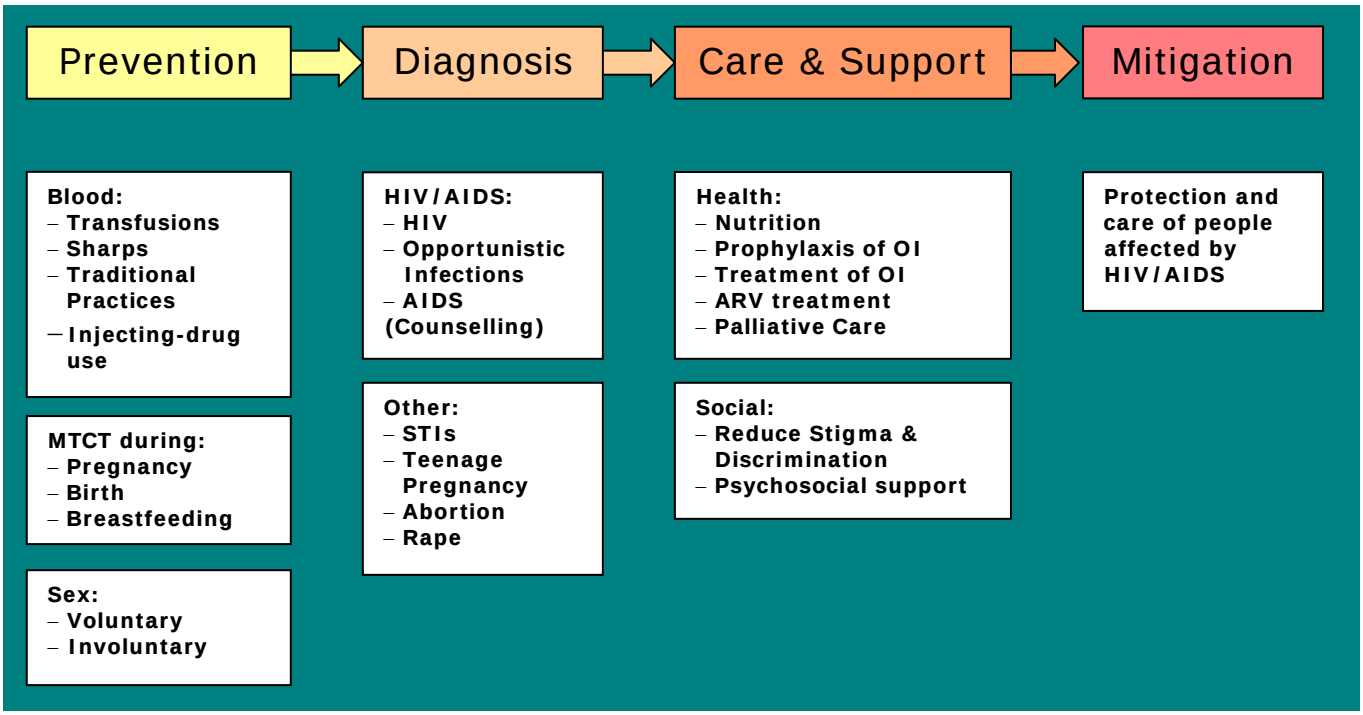
Intermediaries

It is not uncommon that stakeholders from all levels interact within one project, as funding passes through many intermediaries: For example a European government gives money to UNICEF, who uses a part, gives a part to the national AIDS programme, and a part to an international NGO. The national AIDS programme uses a part, gives a part to its committees in the provinces, and a part to some local organisations. The international NGO uses a part, and gives a part to the district AIDS committee and to a national NGO...
The added value of intermediaries is not always obvious; they often lack the time, staff, and technical expertise which is required for adequate project support. One should question for each intermediary what its added value is, and whether it cannot be left out.

Response to HIV/AIDS

The UN Declaration of Commitment on HIV/AIDS (June 2001) gives a clear description of what needs to be done in the battle against HIV/AIDS, and outlines the key responsibilities of state actors. Moreover, there are many guidelines, toolkits, manuals, policies and strategic papers which describe how these goals can be achieved. The humanitarian response to HIV/AIDS in the Great Lakes region is not so different from that in non conflict areas, except for the fact that in a complex emergency there are so many more actors, and funding is more short term natured, which causes competition and a scattered response. Lack of information, planning and coordination seem to be the major obstacles. In this section an attempt is made to provide some generalisations on the technical side, or content, of the response.

In the full report the following model, which pictures the continuum of prevention, diagnosis, care & support, and impact mitigation, is shown twice:
Once it is shown with links to a draft document on standards, recommendations and resources[4], and the other time it links to the overall response in Rwanda, Burundi and Eastern DRC[5], of which this section gives a summarised outline.



Prevention

Transmission through blood and bodily fluids

Blood transfusions: In the region Blood banks are centralised in the major hospitals in the capital and larger cities. Blood is collected from donors in the provinces, tested and stored in the blood bank, and distributed to hospitals. Officially transfusions are only done in hospitals, though there are many stories of transfusions done in health centres (especially in DRC). Blood is tested for HIV, syphilis and hepatitis. Some hospitals use ELISA, and some use rapid tests for HIV. In general one can say that testing is done properly, but there are not enough testing centres.

Universal precautions are usually well observed according to healthcare workers; In the ten health centres visited there were disposable needles and syringes, and incinerators.

Transmission through traditional practices (scarring, cutting out the uvula, circumcisions etc.) is not much emphasized. The issue was mentioned only in the Save the Children UK project in Gitega. Health educators in Giheta displaced persons camps did have special education sessions on this with the camp population (though not with the traditional practitioners).

Injecting drug use has not been mentioned as an issue in this region.

[4] http://cerebellum.tiscaliweb.nl/standards/home.htm
[5] http://cerebellum.tiscaliweb.nl/my_project/problem.htm#how

Transmission from mother to child

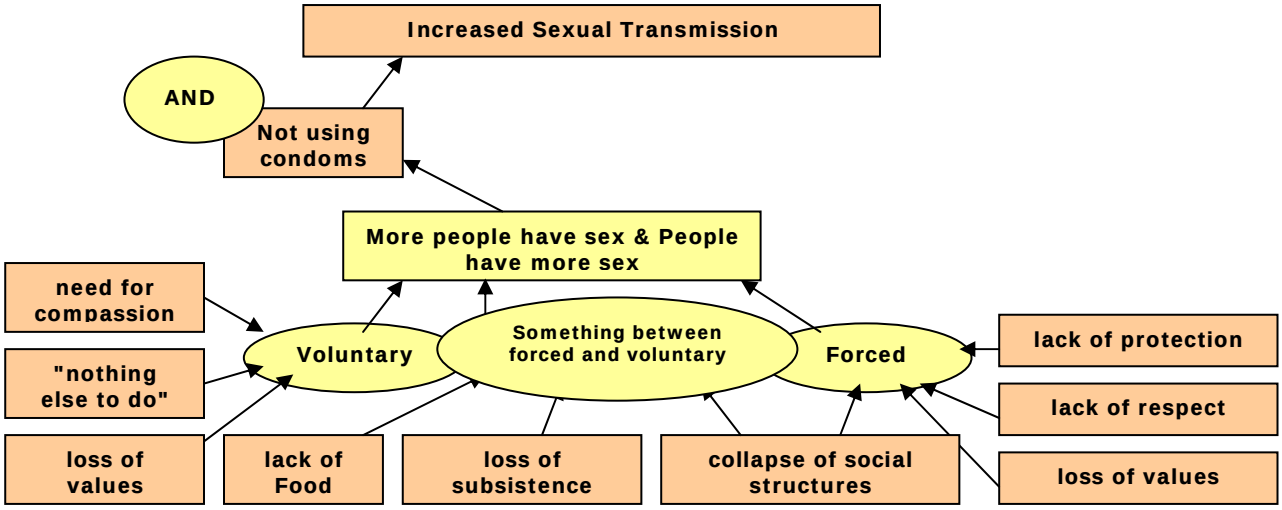
Programmes for prevention of mother to child transmission (PMTCT) are still in a pilot phase in Rwanda and Burundi, and there are no PMTCT programmes in Goma or Bukavu.
In Rwanda there are 28 centres for PMTCT throughout the country. The Treatment and Research on AIDS Centre (TRAC) of the Ministry of Health is the coordinating body for all pilots. UNICEF and Prime II (funded by USAID) pay for the salary of the co-ordinators, and provide materials and reagents for testing. In Burundi there is one pilot project in Bujumbura.

Problems mentioned in Rwanda:

- ✓ Many women do not deliver in hospital and are lost to follow-up.
- ✓ There is no antiretroviral treatment for the mother (or child) after delivery. This means that the mother is likely to die in a few years and the child will become an orphan.
- ✓ The husbands of the women, or fathers of the children, are hardly ever tested.

Sexual transmission of HIV/AIDS

The diagram below demonstrates the increased risk of sexual transmission of HIV/AIDS in emergency settings.



The prevention of sexual transmission is very difficult in the region because sex is a huge taboo. One cannot talk about sex. Neither in the culture of most donors or implementing organisations, nor in the culture of the beneficiaries.

Many projects exist for awareness raising, information, education and communication (IEC), and behaviour change communication (BCC), though it is impossible to judge on their quality. Some projects are undoubtedly very good, others might be bad, but it is very hard to tell as their impact is not measured.

Diagnosis

The true impact of the HIV/AIDS epidemic can only be known if infected people come forward. However, by the time many patients seek care, their HIV has already developed into AIDS. Hence, awareness of the disease among the general population needs to be enhanced. In this context, all stakeholders should be encouraged to improve systems for HIV/AIDS diagnosis[6].

diagnosis of HIV

Among the population the demand for HIV-tests is increasing, and places for voluntary counselling and testing (VCT) are rapidly increasing in the region. This is a very positive trend. Rwanda has 28 VCT centres registered with TRAC; Burundi has over 80 VCT centres throughout the country. Both countries have established a sound protocol using different rapid tests for initial testing and confirmation.

VCT centres can play a great role in coordinating between prevention and care programmes. SWAA and Caritas in Gitega (Burundi) are examples of local organisations which have managed well to establish this link between prevention and care.

Difficulties mentioned:

- Follow-up: Most of the staff in VCT centres in Rwanda complained that they had nothing to offer when someone is tested positive. In Burundi some VCT centres have a good system for follow-up in which PLWHA are registered and enter into a care and support programme. Nevertheless, there are still not enough places for follow-up and support of PLWHA outside the capital cities.
- Feed-back and documentation: In both countries there is a need for improved (confidential) registration of PLWHA which records socio-demographic data, and can serve as feed-back into prevention programmes. Knowing who is infected with HIV, can help targeting the most vulnerable at a local or district level.

diagnosis and reporting of opportunistic infections and AIDS

Opportunistic infections and cases of AIDS are not recorded systematically.

diagnosis and reporting of STIs, teenage pregnancies, abortions and rape

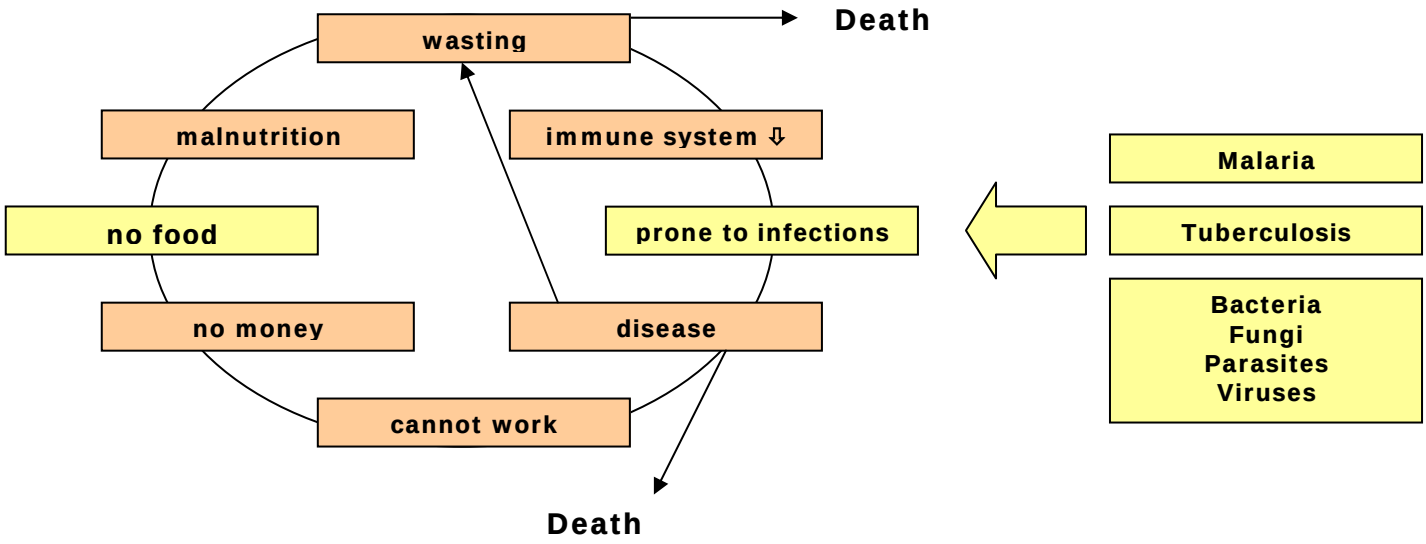
Apparently STIs, teenage pregnancies, abortions and rape are very prevalent, though they are not reported. National protocols for syndromic management exist, and one can find health centres where they are applied, though in most rural health centres they have not yet been implemented.

Care and Support for PLWHA

nutrition

Food, or the lack of it, is one of the most important factors for the health of PLWHA in the region. The diagram below shows the interrelationship between malnutrition and the susceptibility to infections.
There are many local associations that distribute food in home based care settings. Most of the food for these projects is donated by the World Food Programme.

[6] UNAIDS. Managing care: lessons from practice: Pedro Cahn, Jeffrey O'Malley, Mandeep Dhaliwal, Vinh Kim Nguyen, and Carlos Zala



prophylaxis of opportunistic infections

Prophylaxis for opportunistic infections is not yet given systematically, though in Burundi Co-trimoxazole is given to PLWHA as soon as tested positive in all VCT centres managed by SWAA and Caritas, and MSF-H in Bukavu administers INH prophylaxis (to prevent TB) as well as Co-trimoxazole in their centre.

treatment of opportunistic infections

Many small local associations provide home based care, though very few provide treatment for opportunistic infections. Most of these associations are supported by the church and by community initiatives, and some occasionally receive donations of drugs, which they administer to their patients. It must be said that most PLWHA do not know their sero-status until they develop severe illnesses and develop AIDS. It is very difficult to treat opportunistic infections at an early stage as they can often not be distinguished from all the other diseases that are so prevalent in the region.

ARV treatment

In Rwanda only 520 people receive highly active antiretroviral therapy (HAART). Antiretroviral (ARV) treatment is available at cost in three hospitals: King Faysal, KHC and Butare. Rwanda does not purchase generic ARV drugs because they are afraid that the quality is not up to par with the branded ARVs.
In Burundi ARV is available only in Bujumbura (though doctors in provincial hospitals have received training on the administration and follow-up of HAART). Many different ARVs are available, and prices for triple-therapy (including a protease inhibitor) range from 26,000 to 60,000 Burundi Francs per month (= ± $26 to $60 US). The local network for PLWHA Association Nationale de Soutien aux Séropositifs et Sidéens (ANSS) has taken a leading role in making ARVs available.
In E-DRC ARV treatment is not yet available in the normal health system. However, there is one NGO in Goma (DOCS), which provides double-therapy consisting of Videx® and Zerit®, i.e. without the (most expensive) protease inhibitors. Treatment costs $60 US per month.

palliative care

Palliative care is not an alternative to other models of health care. It is not in competition with efforts to provide antiretroviral and other advanced therapies, nor is it a poor relative to be implemented where such therapies are currently inaccessible. It is an essential part of a comprehensive health care system, which is missing in many developing countries, including the Great Lakes Region, and must not be neglected in the efforts to provide greater accessibility to more technical drugs and therapies[7].

[7] Palliative care: Issues and challenges Sue Lucas, May 2002

reduction of stigma and discrimination

Stigmatising perceptions of HIV see it as a life-threatening disease, associated with sex or stigmatised behaviours such as drug use, and conflicting with moral beliefs about choice and responsibility for disease. Stigma generates denial and secrecy about HIV/AIDS, which in turn lead to discrimination –people are treated unfairly because of their sero-status. Thus, people are blamed and victimised, social exclusion and divisions are reinforced and HIV infections continue to emerge. The greater the silence surrounding HIV, the more the stigma and discrimination directed towards people with HIV[8].

In Burundi the stigma and discrimination of PLWHA seems less than in Rwanda and E-DRC. Though no data exist to substantiate this observation, it would be interesting to analyse the reasons. One noticeable difference in Burundi is the dynamism of groups for PLWHA, and the fact that some PLWHA in high positions have disclosed their sero-status.

psychosocial support

Psychosocial support to PLWHA and their families is not provided systematically or professionally, but there are countless small organisations and church groups that provide some kind of moral and or spiritual support.

Impact mitigation

The larger International NGOs and UN agencies have not yet engaged into programmes mitigating the impact of the epidemic, though many local associations and NGOs which have projects for people *infected with* HIV/AIDS, also target people *affected by* HIV/AIDS. Orphans and widows should be protected from abuse, violence, exploitation, trafficking and discrimination. They should be protected from loss of inheritance, and they should have access to psychosocial, health and education services.

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What are the gaps?

It is hard to provide judgement on the quality of the response, as nobody has the overall picture of what is being done in these countries. Among the many different actors there are inevitably some that do excellent work, some that waste all their money, and there is probably a whole spectrum that holds the middle between these extremes.
It goes beyond the scope of this research to assess the quality of each individual project or organisation. One can conclude however, that the response is scattered due to a critical lack of coordination between different actors. Most organisations do not know what others are doing, do not have access to each others' documents, and there is no structured mutual learning regarding successes and mistakes. What is more, most organisations do not learn from their own successes and mistakes, as they do not measure the impact of their work.
Consequently, one can conclude that there is a pressing need to set standards for performance, improve mechanisms for measuring impact and quality, and to create systems for sharing information, which will enhance transparency and accountability.

[8] UNAIDS. Managing care: lessons from practice: Pedro Cahn, Jeffrey O'Malley, Mandeep Dhaliwal, Vinh Kim Nguyen, and Carlos Zala

Next Steps

Objective 3: To build humanitarian organisations capacity to respond to HIV/AIDS in emergency settings.

In order to build on humanitarian organisations' capacity to respond to HIV/AIDS in emergency settings, the first step should be to share information that can lead to improve: 1. the quality of the response (by providing standards, guidelines, toolkits and manuals), 2. the coordination of the response (by showing who does what), and 3. access to funds (by showing which donors will fund what kind of projects and organisations).

How can we improve access to information?

By establishing 'Information Centres', or Approaches for 'Field-Based Information Management'[9]; in other words, by setting up a local, web-based, or electronic system for sharing information between various stakeholders within each country.

In order to be more effective in their programmes,

A) Organisations should know:

1. the scope of the problem in the country
2. what others are doing
3. which interventions work best
4. what is most cost-effective

B) Donors should provide more clarity as to:

1. who is funding which organisations
2. how much funds are available
3. what kind of programmes they fund
4. how and when funds can be accessed

In the boxes within the text below, one can read how a central point for collecting and updating data can be of use in each of these points when data is made available to all stakeholders:

A) Organisations:

1) Organisations should know the scope of the problem before starting interventions

⇨ A central point where studies and epidemiological data are collected, updated and made available, could be useful for planning new interventions.

It is not clear how organisations decide what HIV intervention they will focus on; Epidemiological data are not readily available, and situational analyses, needs assessments, vulnerability and behavioural studies are often done halfway through a project, without using the results to start new projects or modify existing strategies. Very often reports end up in drawers and on shelves, without being used or shared. In Rwanda and Burundi the National AIDS Control Programme and UNAIDS knew about many organisations that had conducted studies, though they either did not have the report, or it was very cumbersome to reproduce it. Local organisations which have originated from community initiatives sometimes have a better understanding of the situation than their international counterparts (or national counterparts from the capital), though usually lack the means to make this information explicit.

[9] OCHA. Humanitarian Information Centres: Establishing coherent approaches to field-based information management in emergencies. March 2001 http://www.reliefweb.int/symposium/InfoCenters.htm

2) Organisations should know which organisation is doing what

It is quite difficult to find out what all organisations do where, as there are very many organisations ranging from small local associations to large international NGOs and UN agencies.

⇨ A central point where information about current projects and actors is collected, updated and made available, could provide a first step to avoiding duplication, and ensuring a more equitable distribution of assistance in the future.

In one place you can have one organisation doing VCT, various organisations doing IEC, an organisation distributing condoms, another that does STD treatment, one or two that care for orphans, one that gives psycho-social support to PLWHA, and one that supports PMTCT. In other places you will find that one organisation covers three of these topics, and there is no-one else for the rest...

Co-ordination mechanisms exist mostly for UN, large international NGOs and the national programme, though do not sufficiently include implementing organisations. Proposals, reports and evaluations are often not shared systematically, or list objectives which are so broad and vague, that it is hard to tell what is actually being done.

3) Organisations should know which interventions work and which don't

Most organisations cannot say how many people they have reached, and whether their interventions have an impact or not. If evaluations are made, they are usually done by external consultants at the end of a project, and not discussed with the implementing teams. Evaluations of projects that do not work are never published, and in general successes tend to be exaggerated in order to get new funds.

Besides not knowing whether their own interventions work or not, organisations do not make sufficient use of the experience of others. There is a tendency to re-invent the wheel, despite the existence of many good guidelines, policy- and strategy papers, handbooks, manuals, and other documents.
Most documents are available in country but are spread over the various libraries and documentation centres of different organisations and it is difficult to get copies.
New publications are usually distributed to heads of agencies, and often do not reach the technical people who implement the projects, or are not translated into the language of the country.
Though many people do have access to internet, this is often only in cyber cafés, or at the office of another organisation. These circumstances do not favour the downloading of large pdf files, or the printing of many page documents.

⇨ A central point where 'best practices', guidelines, toolkits and manuals are collected, and made available, could be useful if there are facilities to make electronic copies and/or print-outs.

4) Organisations should know who does what best and in the most cost effective way

When one looks at some of the project proposals it seems like organisations would like to solve *all* the problems related to poverty and HIV/AIDS. These over-ambitious objectives result in a narrow range of activities at a micro level which are hard to scale up. Many projects are called "pilots" to justify the uncertainty of their outcome, without having proper means for measuring their impact.

Among the many different actors there are inevitably some that do excellent work, some that waste all the money, and some that do something in between. However,

⇨ A central point where impact studies and financial data are collected and made available would give better insight on what is being spent, and could provide an indication for budgeting new interventions.

there are no means to assess who does what well as long as there are no proper systems for monitoring and evaluation, and there is no transparency of funding and expenditures. Moreover, many organisations do not implement projects themselves, but act as intermediaries between donors and implementing agencies. The added value of these intermediaries is not always obvious; they often lack the time, staff, and technical expertise which is required for adequate project support. One should question for each intermediary what its added value is, and whether or not it can be left out.

B) Donors:

1) Donors should provide more clarity as to who is funding who

It is very hard to get a good overview of who is doing what, and how much money is being spent, as there are many different means of funding. The many different donors have different mechanisms for funding: Some provide funds to the government, or directly to the national AIDS programme; Some fund various UN-agencies, who do not implement projects, but act as intermediaries for projects by local or international NGOs; Some fund international NGOs who either pass on the money to local NGOs, or implement projects themselves; Some fund implementing agencies, or implement themselves; and others use a mixture of all these funding mechanisms.

⇨ A central point where information about donors' current funding in country is collected, updated and made available, could provide a first step to avoiding duplication, and ensuring a more equitable distribution of assistance in the future.

Funding for HIV/AIDS projects comes from governments, international financial institutions (WorldBank), the Global Fund to fight AIDS, tuberculosis and malaria, a large array of private institutions and foundations (Gates, Soros, Turner etc.), and international organisations (Faith based Organisations, Red Cross Societies, and International NGOs)

2) Donors should provide more clarity as to how much funds are available

⇨ A central point with information about donors' future commitments in country

Most international donors do not know which amounts of funds are disbursed to the various stakeholders in country. Representatives of donors in country (EU, WorldBank, and government's development agencies like DFID, USAID and GTZ) do communicate with each other from time to time, though there are no structured mechanisms for coordination, and there are no means to assess the total of funds spent on HIV/AIDS.

3) Donors should provide more clarity as to who funds what

There is a large variety in the degree to which donors want to have control over the content of programmes and projects. Some donors have technical departments which specialise in HIV/AIDS, and finance projects according to their own policies. Others base the amount and type of funds on the proposals they receive. In general donors tend to have a preference for projects aimed at prevention, though in the new country plans for Rwanda and Burundi large sums

⇨ A central point with information about donors' funding policies and preferences in country

have been reserved for care & support for people infected with and/or affected by HIV/AIDS.

4) Donors should provide more clarity as to how and when funds can be accessed

Donors tend to increase the 'earmarking' of funds, though it is often not clear how this is effected; The criteria for support are not transparent, and the ability of local actors to access support depends a lot on personal networks and contacts.
Funding cycles differ per donor and future funds are often unpredictable and short-term natured.

⇨ A central point with criteria for funding, formats for proposals and budgets, and calls for proposals

Summarising the information in the boxes, an information system could contain the following information:

- studies and epidemiological data
- information about current projects and actors
- 'best practices', guidelines, toolkits and manuals
- impact studies
- financial data
- information about donors' current funding
- information about donors' future commitments
- information about donors' funding policies and preferences
- criteria for funding, formats for proposals and budgets, and calls for proposals

Practical considerations:

As a start, the framework made for Kigali, Ruhengeri, Goma, Bukavu, Bujumbura and Gitega can be used as a beginning for a larger database.
(see: http://cerebellum.tiscaliweb.nl/my_project/default_Great_Lakes.htm)

This framework needs to be edited and put into a more professional format. It also needs to be translated into French, so it can be used by a wider audience.

In order for such a system to work, it should have 'ownership' in-country and organisations as well as donors should 'buy into the concept', as they will be the ones providing the information and using it. Though first reactions from people in the field have been very positive, they need to be consulted on the usefulness of certain information, and the minimum requirements of the database. (suggestions are provided in the annexe)

As not all organisations have good internet connections the following facilities should be available:

- possibility to copy the whole database on CD-ROM
- possibility to copy files on floppy disks
- possibility to print out documents
- possibility to order manuals, toolkits and guidelines locally
- possibility to access the system on a shared computer

Who would be able and willing to develop, manage and maintain such a system?

Several parties should be considered, and the most obvious are:

- The National AIDS Control Programme, or one of its subsidiaries
  ⇨ as they are supposed to have access to all information from all stakeholders
- UNAIDS
  ⇨ as coordinating body for HIV/AIDS among all UN agencies

Other options that are less obvious should be looked into as well:

- UNDP
  ⇨ as it already hosts a website in all three countries
- OCHA
  ⇨ as OCHA has a mandate for coordination, and is used to collecting and updating information from many different stakeholders (they manage reliefweb and provide briefing packs on each country)
- The Great Lake Initiative on AIDS (GLIA)
  ⇨ as they have planned to create an 'internet-hub' for local organisations in the region
- National Centre for population and statistics
- Local NGOs
- Other UN-agencies, not mentioned above
- International NGOs
- Universities
- Internet Service Providers
- Private companies (??)

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Annexes

List of acronyms

AAD	Association pour l'assistance aux Déshérités
ABS	Alliance burundaise contre le SIDA
ABUBEF	Association burundaise pour le Bien être familial
ACOLSI-PNK	Action et Concertations pour la lutte contre le SIDA – Plate Forme du Nord Kivu
ACORD	Agency for Co-operation and Research in Development
ACSB	Action contre le SIDA au Burundi
ACVS	Action chrétienne auprès des PVVS
ADRA	Adventist Development and Relief Agency
AFEDI	Action des Femmes pour le Développement Intégral
AGB	Association des Guides du Burundi
AHA	African Humanitarian Action
AIDS	Acquired Immune Deficiency Syndrome
AJS	Association des jeunes unis contre le SIDA
ALP	Association de Lutte contre la Pauvreté
ANSP	Association Nationale des Séropositifs
ANSS	Association nationale de soutien aux séropositifs et sidéens
APAS	Appui aux Personnes Atteintes du Sida
APECOS	Association de prise en charge des orphelins du SIDA
APOPI	Appui aux orphelins du SIDA et aux personnes infectées par le VIH
APVS	Appui Psychosocial des Victimes du Sida
ARBEF	Association Rwandaise de Bien Etre Familiale
ARC	American Refugee Commission
ARTS	Association pour recoudre le tissu social
ARV	Anti-Retroviral
ASB	Association des scouts du Burundi
ASM	Assistance aux malades du SIDA ,
ATRABU	Association des Transporteurs
ATRAPRABU	Association des tradi-praticiens du Burundi
AVEGA	Association des Veuves de Génocide
AVISI	Association d'aide aux victimes du SIDA
BMZ	The Federal Ministry for Economic Cooperation and Development of Germany
BNEC	Bureau national de l'enseignement catholique
BVES	Bureau pour le Volontariat au service de l'Enfance et de la Santé
CAP	UN Consolidated Appeals Process
CDC	Centre for Disease Control
CERPROMET	Centre de recherche et de promotion de la médecine traditionnelle ,
CESAB	Centre d'étude et de sensibilisation pour l'action sociale au Burundi
CIDA	Canadian International Development Agency
CNJR	Centre Nationale des Jeunes Chrétiens
CNLS	Commission Nationale de Lutte contre le SIDA
COMIBU	Communauté Islamique du Burundi (Commission de lutte contre le sida),
CPAJ	Collectif pour la promotion des associations des jeunes
CPLS	Commission Provinciale de Lutte contre le SIDA
CRB	Croix Rouge du Burundi
CRS	Catholic Relief Services
DDG	German Development Group
DFID	Department for International Development
DRC	Democratic Republic of Congo
DVS	Association des donneurs volontaires de sang

ECA	United Nations Economic Commission for Africa
EEDB	Eglise Episcopale - Diocèse de Bujumbura
EJIAM	Association d'encadrement des jeunes inoccupés par les activités ménagères
EU	European Union
FAO	Food and Agriculture Organization of the United Nations
FEB	Fondation pour l'Enfance au Burundi
FESCO	Fédération de Scouts Congolais
FFP	Fondation Femmes Plus
FHI	Family Health International
FIC	Foyer islamique de la charité
FORSE	Forum d'assistance aux Orphelins, aux victimes du SIDA & aux Séropositifs
FUS	Force universitaire contre le SIDA
FVS	Famille pour vaincre le SIDA
GGB	Good generation of Burundi
GLIA	Great Lakes Initiative on AIDS
GTZ	Deutsche Gezellschaft für Technische Zusammenarbeit
HAART	Highly Active Antiretroviral Therapy
HI	Handicap International
HIV	Human Immune-deficiency Virus
ICRC	International Committee of the Red Cross
DP	Internally Displaced Person
IFRC	International Federation of Red Cross and Red Crescent Societies
ILO	International Labour Organisation
IOM	International Office for Migration
IPPF	International Planned Parenthood Federation
IRC	International Rescue Committee
ISF	Infirmiers sans frontière
JRS	Jesuit Refugee Services
JSR	Jeunesse solidaire et responsable
MAP	Multi-country AIDS Programme
MESPS	Mutualité d'espoir et soutien des personnes atteintes du SIDA
MINALOC	Ministry of Local Administration and Social Affairs
MOFA	Japan's Ministry of Foreign Affairs .
MSF	Médecins Sans Frontières
MTCT	Mother To Child Transmission
NGO	Non-Governmental Organisation
NPA	Norwegian People's Aid
PACFA	Protection and Care of Families Against HIV/AIDS
PJSD	Programme des jeunes non scolarisés et déscolarisés
PLWHA	People Living With HIV/AIDS
PNLS	Programme Nationale de Lutte contre le SIDA
PSI	Population Services International
REDS	Réseau National Ethique, Droit et VIH
RJSI	Rassemblement des jeunes contre le SIDA
SADOMS	Centre mobile des soins et assistance à domicile des malades du SIDA
SCF	Save the Children Fund
SIDA	Swedish International Development Assistance
SIPAA	Support to the International partnership against AIDS in Africa
SOB	Solidarité pour les orphelins du Burundi
SORETO	Solidarité pour le redressement des toxicomanes
SRF	Solidarité-Renaissance -Fraternité
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
SWAA	Society for Women and AIDS in Africa
TRAC	Treatment and Research on AIDS Centre
UNAIDS	Joint United Nations Programme on AIDS

UNCRC	United Nations Convention on the Rights of the Child
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session
UNHCR	United Nations High Commission for Refugees
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
USAID	The United States Agency for International Development
VCT	Voluntary Counselling and Testing
WFP	World Food Programme
WHO	World Health Organisation

Information that could be provided in the database:

- **studies and epidemiological data**
  ⇨ most is available in-country.
  - ✓ maps of country
  - ✓ population data
  - ✓ HIV/AIDS data (incidence, prevalence, death rates and causes)
    ⇨ breakdown demographics / later: data from VCT centres
  - ✓ Health statistics ⇨ including STDs, teenage pregnancies, abortions
  - ✓ health infrastructure (hospitals, clinics)
  - ✓ reports of KAP surveys, focus group studies etc.

- **information about current projects and actors**
  ⇨ use this research, studies of National AIDS Programme, WorldBank, UNAIDS and Actionaid. send draft to all organisations and donors for updates and additions.
  - ✓ searchable database with listings per actor, per donor, per topic, per geographical area, and per group of beneficiaries
  - ✓ links to websites of all actors

- **'best practices', guidelines, toolkits and manuals**
  ⇨ use this research as basis. Ask all actors for additions.
  - ✓ downloadable documents listed per topic, per actor, per donor, per geographical area, and per group of beneficiaries
  - ✓ national protocols
  - ✓ links to resource sites

- **impact studies**
  ⇨ ask actors, especially donors, whether these exist
  - ✓ reports of studies that have a measured impact (and of those that have not)

- **financial data**
  ⇨ some data available. Needs to be converted in same currency and time-frame. Ask all actors for additions. Suggestions on format (?)
  - ✓ national budget
  - ✓ budgets

- **information about donors' current funding**
  ⇨ some data available (mainly governments). Ask all donors (sensitive information?)
  - ✓ current grants listed per donor, per topic, per actor, per geographical area, and per group of beneficiaries
  - ✓ links to donors websites

- **information about donors' future commitments**
  ⇨ some data available. Ask donors. (will they know?)
  - ✓ list funds earmarked for country

- **information about donors' funding policies and preferences**
  ⇨ some data available. Ask donors.
  - ✓ list who is in principle willing to fund what per donor, per topic, per actor, per geographical area, and per group of beneficiaries
  - ✓ links to donors website

- **criteria for funding, formats for proposals and budgets, and calls for proposals**
  ⇨ some data available. Ask donors.
  - ✓ list per donor, per topic, per actor, per geographical area, and per group of beneficiaries

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