Uganda Red Cross Society/Norwegian Red Cross

Community Home Based Care for PLWHA Projects in Kampala South and Katakwi/Soroti

Mid-term evaluation

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LIST OF ACRONYMS AND ABBREVIATIONS

ABFC	Assistant Branch Field Coordinator
ACP	Aids Control Program
AIC	AIDS Information Centre
AIDS	Acquired Immunodeficiency Syndrome
ART	Anti Retroviral Treatment
ARVs	Anti Retrovirals
BFC	Branch Field Coordinator
CBHC	Community Based Health Care
CBO	Community Based Organisation
CHW	Community Health Workers
CORPS	Community's Own Resource Persons
CSW	Commercial Sex Workers
DAC	District AIDS Committee
DDHS	District Director of Health Services
DHS (C&C)	Director of Health Services (Community & Clinical)
DRC	Danish Red Cross
DOTS	Directly Observed Treatment
FA	First Aid
GIPA	Greater Involvement of People Living with HIV/AIDS
HBC	Home Based Care
HCF	Home Care Facilitators
HIV	Human Immunodeficiency Virus
IDP	Internally Displaced People
IEC	Information Education and Counselling
IFRC societies	International Federation of the Red Cross and Red Crescent
IGAs	Income Generating Activities
KAPB	Knowledge, Attitudes, Practices and Behaviour
MAPS	Multi-Country AIDS Project
MOH	Ministry of Health
NGO	Non Governmental Organisations

OI	Opportunistic Infections
OVC	Orphans and Vulnerable Children
PHA	People Having AIDS
PHAST	Participatory Hygiene and Sanitation Transformation
PHC	Primary Health Care
PLWA	People Living With AIDS
PLWHA	People Living With HIV and AIDS
PMC	Project Management Comittee
RC	Red Cross
STD/ACP	Sexually Transmitted Diseases/AIDS Control Programme
STI	Sexually Transmitted Infections
TASO	The AIDS Support Organisation
TB	Tuberculosis
UAC	Uganda AIDS Commission
UCBHCA	Uganda Community Based Health Care Association
Ug. Shillings	Uganda Shillings
UNICEF	United Nations Children's Fund
URCS	Uganda Red Cross Society
VCT	Voluntary Counseling and Testing
WFP	World Food Programme
WHO	World Health Organisation

Executive summary

The Uganda Red Cross Society (URCS) community home based HIV/AIDS care project supported by the Norwegian Red Cross was initiated in May – June 2002 and implementation started in September 2002. It supports two branches of URCS, that is Kampala South (parishes of Gaba, Kansanga and Kabalagala) and Soroti (Kapelebyong sub county) to carry out Home Based Care (HBC) for People Living With HIV/AIDS (PLWHA) in their communities.

The Project objectives were to:

- Build the capacity within the two Uganda Red Cross Society branches and communities for mitigation and support of PLWHA,
- Provide basic counselling support to people living with HIV/AIDS and their families,
- Minimize the negative social impact caused by HIV/AIDS through material support to PLWHA and their families, and
- Sensitize the public and promote positive attitude towards people with HIV/AIDS and their families (anti-stigma and anti–discrimination campaign).

The project implementation has now been going on for nearly two years and a mid term review was carried out to look at its contribution to the fight against HIV/AIDS in the two communities and the direct and indirect beneficiaries as well as the lessons learnt and plan the way forward.

One of the major findings is that the project areas are located in excellent locations with regard to outreach for the most vulnerable people living with HIV/AIDS. The fact that URCS has established itself as a community based organisation and is not only relief oriented, has improved the capacity for delivering on the project objectives.

There is excellent involvement of the PLWHA at all levels of the program (GIPA principles in action). There was extraordinary commitment at all levels (Headquarter staff, branch board, branch staff, project officers and volunteers). Program strategies and implementation are in line with global and national policies and strategic plans aimed towards HIV/AIDS management.

The project is commendable and doing good work however there are few challenges that can be addressed by the URCS Management in order to consolidate their services even further. These are highlighted as recommendations below.

Recommendations

1) There is need to improve communication, networking and collaborative efforts at all levels (national, district, branch and community levels) in a bid to promote URCS Home Based Care Program, advocate on behalf of PLWHA and for resource mobilisation. For example, the Kampala South branch could benefit from wider representation on its Project Management Committee.
2) More resources should be invested in capacity building especially for the project officers (in areas such as HIV/AIDS communication and basic nursing skills, for example) and for a start the possibility of drawing on the resources of key partners could be explored.
3) Good documentation practice of all relevant project documents for monitoring performance should be encouraged including documentation of important decision making processes.
4) To improve the success rate of the IGAs, the URCS should provide training to the beneficiaries in the generation and management of savings. Promoting successful IGAs through publicity and bonuses could provide incentives for improving on the scheme.
5) Psycho-emotional support to HBCF should be further structured and organized into a proper psychological support program for volunteers. In order to guarantee that the HBCF trained are competent, URCS should provide course curriculum, training manuals and topical handouts for participants (in local languages) to the project officers as well as using as much as possible case studies from within the project areas to train the volunteers. It is also urgent to equip HBCF with nursing kits, torch, boots, and umbrella to improve conditions of work. Additionally, secondary care takers should also obtain the basic nursing equipment to ensure proper nursing care in absence of HBCF.
6) Improve on The Home Visit Forms/records to better categorize clients according to their condition especially by incorporating a check list to better appreciate and capture the patient's situation and needs (e.g. his/her medical, socioeconomic,

physical and emotional conditions). Improving the quality of this Home Visit Form will make it possible in future to measure the quality of care provided by HBCF.

7) It is imperative now to initiate treatment literacy for volunteers and treatment preparedness for the community in light of management of opportunistic infections and ARV scale up for PLWHA.
8) The program for positive living clubs should be further structured and developed more so by encouraging them to network with the PLWHA Forum.
9) KAPB study should be carried out and appropriate local IEC messages developed for targeted groups. In order to measure the behaviour change impact of the projects at household and community levels, it's imperative that baseline surveys be carried out.
10) Considering the fact that URCS Home Based Care Project areas are already involved in ARV drug initiatives, it is recommended that URCS explores its comparative advantage in the provision of ARVs to the rural communities and starts planning for such implementation in a phased manner.

As a way forward, given that insurgency and cattle rustling has disrupted the social structures and economic livelihoods of communities and caused an increase in HIV sero - positivity of up to 23% in the Soroti/Katakwi project area, the URCS can play an important role within community preventive efforts in the area.

If all the above recommendations are implemented, we believe that the URCS would have established a good foundation for further scale-up of the HBC Program.

1.0 Introduction

Uganda is one of the Sub Saharan African countries that have been hardest hit by the HIV/AIDS epidemic. The first case was reported way back in 1982. Since then, data from the surveillance unit of the STD/ACP Ministry of Health HIV/ Surveillance Reports estimated that by the end of 2001, the cumulative number of Ugandans who had been infected by HIV/AIDS was about 2.5 million out of whom 800,000 people had so far died.

In the late 1980s and early 1990s, the HIV prevalence rates in ante natal surveillance sites was approximately 25 – 30%; this has however since declined to the current 6.0 – 6.5%. This has among others resulted from the multi-sector approach to HIV/AIDS including prevention, care and support.

Current estimates are that in Uganda, the number of people living with HIV/AIDS is about 1.1 million and out of this number about 200,000 have clinical AIDS. This places a heavy burden on the health care system and consequently health institutional support cannot cater for this large number of PLWHA in need of care and support.

However, later studies by the MoH also proved that some PLWHA preferred to be cared for outside hospital settings. For example, according to the needs assessment conducted by ACP/MOH way back in 1992, 69% of PLWHAs preferred to be cared for at home. This was partly attributed to the constraints of space, equipment and manpower in hospitals on one hand but also the fear of stigma that come with being hospitalised. And yet, the situation analysis on HBC services for PLWHAs conducted by WHO and MOH in 2001 in 10 districts showed that HBC services were being done on a small scale and mainly spearheaded by NGOs and CBOs. This study raised the voices of those demanding the need to increase on the coverage of HBC services in the country.

In addition there has been a very strong linkage between TB and AIDS. A greater percentage of patients with HIV/AIDS are presenting with Tuberculosis as well. Patients that present with either AIDS or TB or both need care that starts right from the hospital to the household levels and hence the interest in Home Based Care Programs that can address the need of patients and their families, out of the hospital setting.

It is against this background that the Uganda Red Cross Society's Community (URCS) Home Based Care project was conceived. This report contains the results of the mid-term review of the Uganda Red Cross Society Community Home Based Care project for PLHWA in the Kampala South and Soroti branches.

1.1 Program history

Uganda Red Cross Society (URCS), established by an act of Parliament in 1964 as an auxiliary of government, has been involved in HIV/AIDS programs since 1987. The major activities over time have been:

- Home Based Care for PLWHA
- Youth Peer Education
- Community sensitization activities
- IEC material development and behavioural change communication
- Blood Safety program

These activities have been implemented under the integrated health program. The HIV/AIDS activities are also implemented under the overall framework of the National HIV/AIDS response policy especially the national HIV/AIDS policy and the national strategic framework for expansion of HIV/AIDS care and support in Uganda (2001/2 – 2005/6)

1.1.1 The Home Based Care Projects

The overall aims and strategy of home based care projects is to provide referral for prompt treatment to HIV/AIDS patients and other patients that may present with opportunistic infections and long term conditions like Tuberculosis, to offer psychological support to patients and their families, to provide information and education on prevention and care issues on infection e.g. HIV/AIDS and Tuberculosis and to provide spiritual support to patients and their families through pastoral care.

The URCS community home based HIV/AIDS care project was initiated in May – June 2002 with support from the Norwegian Red Cross and implementation started in September 2002. The project supports two branches of URCS, Kampala South (in the parishes of Gaba, Kansanga and Kabalagala) and Soroti (in Kapelebyong sub county) to

carry out home based care of PLWHA in their communities. Below is a description of the above mentioned project branches.

Kampala South

Kampala South is located in the suburbs of the capital city Kampala. The project is implemented in the three parishes of Gaba, Kansanga and Kabalagala. These parishes have some of the city's largest slums, poverty and sex work abound, one straddles a fishing community and because of these factors, the levels of vulnerability to HIV infection are very high. Generally, the livelihood in the city slums is complicated by poor employment opportunities and serious food insecurity leading to desperation among the PLWHA.

Soroti (Katakwi)

Katakwi district, part Soroti branch of URCS is located in the North Eastern part of Uganda. It has a population of 307.032 people (2002 population and housing census). The Project is implemented in Kapelebyong Sub County, which neighbours Karamoja region.

People in the area have been living in IDP camps since 1987 as a result of the insurgency and are under the constant threat from Karamojong warriors. Of late, the Kony rebels, Lords Resistance Army (LRA), have extended to this area further displacing most people to Soroti municipality. Half of the registered clients in the HBC project fled as well as some of the trained home care facilitators. This way, in 2003, the project had to extend into Soroti municipality in order to reach internally displaced clients there until it was frozen after 3 months in mid 2003.

This unsettled life has resulted into severance of family and social ties, causing a rise in commercial sex work and rape. The internally displaced population also has no means of livelihood since their subsistence farming activities have been disrupted by the insurgency. Additionally, service provision is poor and inadequate for the same reason.

1.2 Programme objectives and strategies of URCS

The objectives include the following:

1. To build the capacity within the two Red Cross branches and communities for mitigation and support of PLWHA
2. To provide basic counselling support to people living with HIV/AIDS and their families
3. To minimise the negative social impact caused by HIV/AIDS through material support to PLWHA and their families
4. To sensitize the public and promote positive attitude towards people with HIV/AIDS and their families (anti-stigma and anti-discrimination campaign).

The strategies to assist implementation include the following:

1. Red Cross branch capacity building for response to the epidemic
2. Social mobilization through partnership building with communities and the civil society, networking with AIDS service organizations and primary care providers.
3. Advocacy, intensive IEC focusing on prevention of HIV/AIDS through anti-stigma campaign and community care and support of PLWHA
4. Community capacity building, training of community own resource persons (CORPS) to provide home based care
5. Support of PLWHA through income generating activities to facilitate access to medical care, school fees for children and food security
6. Sharing experiences, borrowing lessons and learning from other national societies and local organizations involved in community home care

The project implementation has now been going on for nearly two years and it was deemed helpful to carry out a review to look at its contribution to the fight against HIV/AIDS on the community and the direct and indirect beneficiaries as well as the lessons learnt and plan the way forward.

1.3 Goal for the Mid-term Review:

The Mid Term Review was conduced in order to review the implementation of the project so far with the view to assess the achievements, lessons learnt and make recommendations on the way forward for the project.

1.4 Methodology used by the evaluation team:

The methodology adopted was participatory which included initial discussions with URCS Headquarters staff, project staff, review of literature, individual interviews both at URCS

Headquarters, Branches and Project areas followed by focus group discussions with all key stakeholders at all levels.

2.0 Project development

This section contains information on all aspects of the URCS Home Based Care project development in both Kampala South and Katakwi/Soroti branches. The aspects covered range from staffing, preventive services, assessments of their impacts at different project levels, to referral and deferral support provided in the project areas.

2.1 Staffing

Each Branch Governing Board includes the following:

1. The Chairman
2. The Vice- Chairman
3. The Treasurer
4. 2 youth
5. 2 women's representatives
6. Branch Field Coordinator
7. 3 Co-opted members (A Police representative, A Health Advisor and Patron of the branch)

Each Branch has the following Staff:

1. Branch Field Coordinator
2. Assistant Branch Field coordinator
3. The Project Officer, HIV/AIDS Project

In addition to the full time staff, by the time of this evaluation, both branches had 50 (25 each) HCFs in total.

2.2 Community Preventive Effort

The aim of this activity is to sensitize the public and promote positive attitude towards people with HIV/AIDS and their families (anti-stigma and anti-discrimination campaign).

Strategies employed to assist implementation

- Social mobilization through partnership building with communities and the civil society, networking with AIDS service organizations and primary care providers

- Self support groups of people living with HIV/AIDS - Red Cross Positive Living Clubs
- Advocacy, intensive IEC focusing on prevention of HIV/AIDS, anti-stigma campaigns and community care and support of PLWHA

2.2.1 Preventive activities undertaken

a). At Central Level

I. Developed IEC messages on stigma and discrimination, nutrition, sanitation in both English and local languages

II. Produced IEC materials (posters and brochures) on stigma and discrimination, nutrition, sanitation. However no flip charts were produced.

III. Involved in anti-stigma and anti-discrimination campaigns countrywide and especially, community sensitization programs through music, dance and drama.

b). At Branch levels

I. Held advocacy meetings with political, civic and opinion leaders at district and community level on stigma and discrimination and causes and prevention of HIV/AIDS

II. Participated in district planning meetings together with other stakeholders to coordinate community HIV/AIDS interventions

III. Collaborated with Uganda Cares to whom clients and secondary beneficiaries from Kapelepyong project area are referred for provision of essential community clinical care (optimistic infections), management and counselling

IV. Twelve positive living clubs formed and supported

V. Carried out social mobilization activities as a core activity. Drama group formed and costumes purchased

VI. Helped those communities that are in hard to reach areas with access to VCT. Three VCT organized and implemented in IDP camps in Kapelebyong. While in Kampala four out of ten KCC clinics provide VCT.

c). At Community level

I. HBC facilitators provided comprehensive home based care to both the primary and secondary beneficiaries.

II. Able to provide IEC messages on both preventive and basic health care and hygiene practices, refer early where necessary and provide psychosocial support thereby contributing to community preventive efforts.

III. Dissemination and membership recruitment in Red Cross.

2.3 Assessment of Impact

a). At Central level

Baseline survey has not been done, against which impact could be assessed.

b). At Branch level

URCS image greatly improved as reported by the district leadership (both the Resident District Commissioner and the District Director of Health services) who were happy with project's impact on:

I. Sensitization and mobilization efforts against HIV/AIDS
II. Anti-stigma and anti-discrimination campaigns
III. Helping in the reconstruction of social fabric in the IDP camps
IV. Health Education at the community level.

Katakwi District branch is now demanding to upgrade from a sub-branch to a full URCS branch. Generally, the enhanced impact of the project is demonstrated by the rising profile of URCS. For example, there was an overall increase in membership recruitment at Soroti Branch:

Soroti Branch		**New Membership**
1.	2002	277
2.	2003	399
3.	2004 to date	290
4.	Total Membership	1101

c). At Community level

Kapelebyong Project Area

According to the Project and Branch Reports, the following observations are made:

I. Level of awareness about HIV/AIDS increased from 10% to 30%

II. The stigma and discrimination reduced from 70% to 60%

III. More people enrolled as Red Cross members and volunteers

IV. 60 people registered as Red Cross life members.

Similarly, the Evaluation Team noted that peer education/out of school audiences were not specifically targeted but are encouraged to participate in positive living clubs.

2.4 IEC

IEC is presently delivered in an unsatisfactory manner and mainly in the English language. There is need to re-design the IEC strategy to ensure that relevant messages in local languages are developed for different target groups to be based on KAPB study findings on misconception, attitudes and practices. Sensitivity to disability, literacy levels, gender and generational differences is very crucial.

2.5 Anti-stigma campaign

Anti - stigma campaigns are held at all levels through meetings, mass media, and reports. These efforts have contributed to lessening the problem of stigma and discrimination in the project areas and Uganda as a whole. They could however also benefit from sensitivity to local differences as noted for IEC above.

2.5.1 Observations

Two main challenges remain namely:

- Self-stigma
- Attitudinal

2.6 Positive living clubs

These are clubs formed as part of support structures for PHAs and for prevention of HIV/AIDS in the communities especially targeting the youth and PLWHA. Ten groups have been formed in the Kapelebyong Project area and two in Kampala South Branch.

What they are doing:

- Meet weekly for about 45 minutes
- Share experiences when they come together
- Talk about self-stigma and discrimination hence, help with break the silence among members who are HIV positive through music, dance and drama
- Carry out mobilization and sensitization about cause and prevention of HIV/AIDS to the community through drama
- Educate each other about positive living
- Inform about VCT and access points (a total of 653 secondary beneficiaries have accessed VCT as a result and over 1000 community members have expressed need for VCT)
- Offer psychosocial support to each other (affected and infected)
- Promote proper condom use
- Disseminate information about Red Cross work
- They participate and monitor income generating activities.

2.6.1 Observations

PLWHA members are well integrated in the clubs together with HIV sero negative members and as a result of the positive clubs many of their members have gone for VCT. Every club meets weekly for about 45 minutes and all of them meet once a week on Fridays, to plan together their activities and visit one PLHWA who is very sick. Topics for the meetings include: HIV/AIDS, how to live positively, planning together and identifying among them the very sick for psychosocial support.

Benefits of the meetings

- Positive living clubs have helped them to strengthen the support structures for themselves and PLWHA.
- Enables them to bring out those that are afraid or suffering from self-stigma

Benefits of being in the club

- Solidarity and unity amongst themselves (support structures available)
- Helps with anti-stigma and anti-discrimination
- Financial mobilization for members who can't afford to buy i.e. basic medicines
- Sharing experiences amongst themselves (testimonials) and this strengthens them
- Economic empowerment of individual PLWHA through IGAs

- Sharing experiences among themselves (testimonials) to strengthen them.

2.6.2 Specific Recommendations

- Get copy of the Positive Development manual developed by GNP+ and promoted by the International Federation of the Red cross for use by Positive Living Clubs
- Invite the PLWHA forum to come and help with building capacity of the Positive living clubs (teach them better on how to go public and to work together)
- Re-design their IEC strategy to ensure relevant messages in local languages are developed for different target groups. At local level, the HCFs and the Positive Living Clubs are key actors in the process of delivering messages to the public. By providing IEC materials, and by establishing a closer working relationship with Positive Living Clubs, the URCS would be able to ensure that the messages forwarded to the public are correct and precise. The audience's perception of these messages should be monitored, i.e. through surveys.
- Encourage religious and traditional social morals.
- Positive Living Clubs should continue to mix sero-positive and negative members
- Other activities such as information and experience sharing, counselling, prevention and community awareness should continue to be encouraged through drama, music, etc.
- The programme for Positive Living Clubs should be structured and developed further
- Community awareness sessions should be restructured to improve on messages for specific target groups.
- There is need to build capacity and knowledge of the Positive Living Clubs about cheap essential foods available locally, for example vegetables, fruits and herbs.

2.6.3 Major Recommendations

In Katakwi/Soroti area, the insurgency and cattle rustling have disrupted the social structures and economic livelihood of the communities. This led to increased HIV sero-positive rate to the tune of 16.8% - 23%, hence, the need for programs on community awareness on preventive measures for HIV/AIDS to continue. Therefore URCS still has a big role to play in community preventive efforts.

However there is need to re-design their IEC strategy to ensure relevant messages in local languages are developed for different target groups to be based on KAPB study findings on misconception, attitudes and practices.

There is a need to take advantage of the Youth Peer Education program available under the youth department to involve the youth in prevention of HIV/AIDS.

Likewise, there is need to integrate other preventive health components at community level i.e., Sanitation, Malaria, and Tuberculosis (see also section 6.4).

2.7 Health Promotion and Education

The Evaluation Team observed the need to carry out baseline surveys to enable the project to measure behavioural change on the impact at household and community level. There is also a need to capture both indirect and secondary beneficiaries as well.

2.8 Global Appreciation

The HBC Program strategies and implementation are in line with global and national policies and strategic plans.

2.9 Home Based Care Facilitators

This section focuses on aspects of recruitment, management, motivation, supervision and retention of Home Based Care Facilitators (HBCFs).

Volunteers have been recruited through advertisement by the branch in the project areas. They are men and women from the communities in which the projects are located, most are mature adults, and they are also referred to as community resource persons in Kapelebyong. For example, 25 were recruited in Kapelebyong, where they are currently caring for 125 beneficiaries. One HBCF is caring for 5 beneficiaries. The gender ratio amongst clients (beneficiaries) is 41 males for 84 females.

The volunteer retention rate has been 24/25. Eight of them went through voluntary counselling and testing, 3 were found to be HIV positive and are by now open about their status and serve as role models within their community. Other volunteers willing to know their sero status were not able to do so due to a shortage of tests at the time of the VCT session organized by the project.

In Kampala South, 25 volunteers were recruited as HBCF to care for 185 beneficiaries. One HBCF is taking care of between 7 to 8 beneficiaries. They are 8 male and 17 female in total, 9 are living with the virus and open about their status. Some of them are also beneficiaries within the project. During the project span, 11 volunteer HBCF left the project and have been replaced.

In both locations, they are bound to their respective branches by a signed 3 months renewable volunteer contractual agreement, which spells out; the reporting lines and requirements, the relationship with the Project Officer and Branch Field Coordinator, their role and principal assignments, and their allowances, being 5000 Ug. Shs per day for 2 days' work per week, together with a bicycle for movement within the project area.

Volunteers operating within the project areas have been provided with T-shirts, caps, etc. This is, however, not sufficient for identification purposes, as many of the HBCFs in Kampala South reportedly have experienced harassment due to lack of identity cards.

In both project areas, the evaluation team was very much impressed by the relevance of the project sites location reaching out to the most vulnerable PLWHA amongst the Ugandan IDP-s in the North and disadvantaged slums of the capital city. The team also recognized the organization's openness towards HIV infection at all levels (Board, management, volunteers and community and interpret it as an internalization of the URCS Policy on HIV and AIDS in workplace and campaign against stigma and discrimination). However none of the RC Board members or the staff interviewed were informed about this policy. For that matter, URCS policy on HIV/AIDS in the workplace should be disseminated and further internalised within the URCS, as well as, communicated outside the organisation to all stakeholders (Government and partners, internal and external as it may explain the necessary costs associated to the management of staff and volunteers living with HIV/AIDS.

2.9.1 Recommendations

URCS Headquarters to provide more guidance to branch and project officers on HBCF identification as volunteers legally bound to the URCS within the project areas.

2.10 Training of Home Based Care facilitators

To date, the HBCF in Kapelebyong, Katakwi have benefited from 3 trainings, 8 days in October 2002, seven days in June 2003, and four days in May 2004. The training was done in partnership with Kamwokya Christian Caring Community, an experienced CBO in Home based and community care and staff from the District Director of Health Services.

In general the time tables presented to the Evaluation team outlining the training contents are good. Nevertheless the course objectives are not properly specified, and there is need for pre and post tests of participant's knowledge. Lectures have so far been preferred against participatory methods like group work, cases studies, and practical nursing care skills demonstration. However the participants were certified with certificates of attendance.

Beneficiaries informed the evaluation team that they were not provided with any workshop or training course reports, or teaching aids which supported the training. Additionally, the project did not provide HBCF with a Home Based Care manual for referral purposes, however HBCFs are encouraged to refer to the few home based care manuals developed by WHO and MOH at their branch office.

In South Kampala, two trainings have been organized; the first training lasted ten days, starting September 20th 2002, and the second, in 2003, had approximately the same time frame. In addition, seven newly recruited home based care facilitators joined the HBCF training in Soroti. The first training was conducted by the Christian Caring Community and Mengo Hospital.

2.10.1 Recommendation

In the absence of a MOH curriculum for HBCF, URCS HQ needs to provide project officers in branches with a course curriculum which specifies the course objectives and contents, time allotted per topic, training and evaluation methods to be used and the certification procedure. It is crucial for URCS to guarantee that the Home based care facilitators trained are competent.

Workshops or training course reports if existing could be used to develop a URCS National Curriculum for HBCF and serve for the development of a Home based care facilitator resource manual or topical handouts for distribution to participants preferably in local

languages, as some of the volunteers met in Kapelebyong and South Kampala have a limited command of English language. As a minimum, the Federation's ARCHI tool kits on house to house Promotion and prevention, HIV&AIDS Home based care and Voluntary Counselling and Testing could be adapted and translated.

Participatory methods using case studies on real life home based care management of HIV and AIDS patients should be preferred throughout the training of HBCF.

Practical nursing skills to be transferred preferably at the bed of the patients (Practice in hospital may be considered).

On the job training by the coach or project officer need to be streamlined into supervisory visits.

2.11 Client's identification

All clients in both project areas went through VCT and the branch got a confirmation of their results. The sero-positivity is the first entry requirement for beneficiaries, while their vulnerability, even if the criteria have yet to be nationally determined, are the second. In Soroti, a set of selection criteria for beneficiaries have been codified, and it is in principle possible for other chronically ill persons like TB or cancer patients to be registered as clients even if HIV negative.

All beneficiaries entering into the project in Soroti and Kampala South are registered through a registration form encapsulating all their important bio data.

However, no particular system has been developed to ensure the confidentiality and anonymity of the clients. No particular client's assessment-needs-form has been developed. Client's needs are assessed and reported in the Home-Visiting Monitoring Tool developed for on-going monitoring of beneficiaries by home based care facilitators in Soroti and Kampala South with slight differences between the two branches. The enrolment of clients is subject to the approval of the Project management committee and project officer in Soroti, and of the Parish leader in Kampala South.

As of today, the current number of clients supported by the project stands at 125 in Kaplebyong, below the foreseen target of 200 and is consisting of 41 males and 84

females. 60% of clients are pertaining to the IDP and 40% to the host population. In Kampala South, the total number is of 185 below the 200 target consisting of 44 males and 141 females located in Kabalagala Parish, Gaba and Kansanga.

The number of secondary beneficiaries in Kaplebyong is estimated to be 631 and 866 in Kampala South. The secondary beneficiary or secondary care takers' particulars do not appear in the registration form of the clients in Soroti Branch but a specific form needs to be developed to register secondary beneficiaries for each of the clients.

2.11.1 Recommendation

URCS HQ should based on the experiences of the two branches come up with a more comprehensive set of criteria to appreciate client's vulnerability.

A proper review of the confidentiality of the data collected on beneficiaries should be undertaken by URCS HQ and the system to store information be developed for implementation by the branches.

2.12 Home visits and day care

Beneficiaries are visited on average 3 times a week by HBCF. Depending on the condition of the person, they can spend up to three hours per beneficiary. Each visit made by the HBCF is recorded in a report form for field home care facilitators in Kampala South and a home visit monitoring tool in Kapelebyong.

Each HBCF fills an individual form for each beneficiary. The form contains the basic information on the beneficiary, name, age, sex, location, problem identified, action taken and comments made by the HBCF in Kapelebyong. And date, activity, name, sex, outcome of the visit and remarks in case of Kampala South. The form provides information on the continuum of care provided to the beneficiary and it is the tool the project officer is using to monitor performance of Home based care facilitators.

Nevertheless, the home visits undertaken by the evaluation team in presence of the HBCF revealed that they need much more guidance on how to assess the patient condition, needs and situation. In Kampala South, HBCF have made an attempt to mark in a notebook left at the beneficiaries' house their observations. These are relatively poor and do not reflect accurately the patient condition to appreciate quality care.

Each report on a beneficiary made by the facilitator is to be approved by the parish leader in Kampala South and one representative of the project committee in Kapelebyong before they are communicated to the respective project officers at the end of the month. It is on this basis that project officers are able to do consolidated reports to the branch management and URCS HQ on a monthly, quarterly and annual basis.

All data pertaining to HBCF outreach activities in Kabelebyong were presented to the team, which was impressed by the quality of the project documentation. The Kampala South Branch may benefit from an exchange visit with the Soroti Branch to improve its performance in data management.

Main activities performed by HBCF include counselling on positive living for beneficiaries together with their relatives, environmental and personal hygiene, cooking and nutritional guidance, referral for VCT, PMTCT, Treatment of opportunistic infections, and access to ARV.

It is to be noted that apart from some gloves supplied in Kapelebyong, HBCF and or secondary caretakers in general are not provided with a home care nursing kit. This makes the work of the HBCF extremely difficult as they are operating in deprived households.

Despite these difficulties, the evaluation team was impressed by the dedication of the HBCF, the cleanliness of beneficiaries, the openness of households and surrounding communities towards HIV and AIDS infection. The care and nutritional support provided, play a significant role in morbidity and mortality reduction, comfort and hope of beneficiaries and households visited.

In the households visited there was evidence of secondary care-taker empowerment. Certainly more focus and efforts should be put by HBCF to implement this very important care strategy to prevent dependency towards the project as some of the beneficiaries may need night and day constant nursing care.

Orphan care is seen as an issue which needs to be tackled separately and with additional resources, impeding any attempt to start planning for children when one or two of the parents are still alive (see section 6.2).

In all households visited, it was difficult to find some substantive medical background information on the beneficiaries' condition and treatment over the last months. When provided, it was scattered all over the personal effects of clients and in bad shape.

In project locations, the coverage and accessibility to safe water and proper sanitation is limited. For example in Katakwi district where Kapelebyong beneficiaries are located, the sanitation coverage is of 25.2% and the safe water coverage of 43%. This situation is even worse in the IDP camps and this calls for better integration of the Home based care programme with the URCS Community Based Health Care program. Malaria prevention and control, access to water and sanitation using the Participatory Hygiene and Sanitation Transformation methodology would also become handy or if not possible on the necessity to collaborate with other specialised agencies.

2.12.1 Recommendations

It is urgent to equip HBCF with basic home based care nursing kits, torch, boots, umbrella and secondary care takers with basic nursing equipment to ensure proper nursing care in the absence of the HBCF.

Home visiting monitoring form can be improved by categorizing clients according to their condition e.g. whether bed ridden, confined at home, ill but mobile, not too ill and mobile and by incorporating a check list to better appreciate the patient situation and needs as well as to be able in the future to measure the quality of care offered by HBCF. Detailed records would be useful if they captured:

- Physical condition: cannot sit alone, walk alone, speak for self, turn in bed, feed self, control vomiting, nature of pain, diarrhoea, weight loss, difficulty in swallowing, etc.
- Need for condoms, education about sexual practices, education about medicines
- Chest infection, non productive coughing, productive without blood, productive with blood, breathing with difficulties

- STI, vaginal discharge foul, non foul vaginal discharge, Urethral discharge, sore on the penis, vaginal sores
- Dermatological, skin rash, itching
- Psychological, lonely, anxious, depressed, confused, cheerful, hungry
- Environment, safe drinking water, clean linen, toilet facilities
- Socio-economic aspects like money to purchase drugs, pay for school fees, food, and
- Spiritual support, counselling, pain medication

This would require more skills on the part of HBCF but once such skills are invested and motivated it would have radically improved modalities for intervening in more focused ways than is presently possible with scanty knowledge. Therefore, if these are incorporated and streamlined in formatting the Home Visiting records it could work. For orphans there is an opportunity to make Memory Books and wills and establish other low-cost psycho-social support programme components (see section 6.2). All medical records of the clients need to be organized and protected in a plastic folder or bag.

More emphasis should also be placed on primary/secondary care givers' role and responsibilities in the provision of care to prevent dependency towards the project and HBCF. As the primary & secondary care givers are empowered, the HBCF ensure mainly monitoring & supervision and can take on board additional clients.

More integration with the URCS CBHC program will greatly benefit clients and households under the Home based care project.

2.13 Food and nutritional support

It is a very crucial component of the project to sustain the beneficiaries' health status through food supplements. However, this is a costly but necessary critical component as it represents a sizeable part of the overall project budget. Every two weeks the food items mentioned below are distributed to each beneficiary. It is based on WFP recommended ration for 5 people. These are:

I. Beans 4kg
II. Posho 10kgs

III. Rice 4kgs
IV. Sugar 3kgs
V. Cooking oil ½ litre
VI. Salt 1kg
VII. Milk powder 2kg

In Kapelebyong, as advice to boost the intake of vitamins, beneficiaries and secondary care takers are encouraged to cultivate green garden around their households. None of the branches seem to have done, or have access to, any recent assessment of nutritional status and needs among the target group. As for other kinds of interventions, it is very important to have a clear picture of the needs and the impact of the intervention (see section 4.2 for further comments on networking).

2.13.1 Recommendations

I. HBCF should monitor proper storage and consumption of food.
II. Project should be provided with a weighing machine and clients weight monitored by HBCF at least once or twice a month preferably.
III. The delivery process and quality control for food should be improved.
IV. URCS in collaboration with other partners should explore ways of acquiring additional nutritional supplements for the beneficiaries.

2.14 Material support

Inadequate levels of material support. It is mainly in form of bicycles provided to the HBCF to enhance their outreach and home visit services. Other material distributed are condoms for preventive information and practices, uniforms and audio-visuals supplied to the drama and music groups that indulge in health communication through popular theatre.

Recommendation

Mosquito nets, bed sheets, blankets and kitchen sets were given out during the initial period of the project; however, they need to be replenished.

2.15 Psychosocial support

This is limited at the moment. Psycho-emotional support to HBCF to be further structured and organized into a proper psychological support programme for volunteers.

2.16 Referral/deferral (VCT, Treatment of OI, ARV)

All clients in both project areas are referred for medical treatment with a form encompassing the minimum information required that is: name, date, age, residence, reason for referral, health unit referred to, and the HBCF responsible for the client. However, there are slight differences between the two branches.

In most cases, clients visited due to their condition include those bed ridden, stage 3 with a TB and others with a neuropathy unable to walk. Clients with stage 4 and TB are referred to private health facilities that are geographically more accessible where they have to pay fee for service, i.e. in Nsambya Home Based Care Programme - where the charge is 1000 Ug.Sh, or at the Kapelebyong Church Dispensary, which is run on a cost recovery scheme. However, as most of the clients enrolled in the program are economically deprived, they are unable to meet the expenses involved with the result that there is no timely access to treatment or some times, no treatment at all.

Regarding the public facilities, free of charge, they are geographically inaccessible for most seriously ill beneficiaries, lack certain specific drugs and involve transportation costs. In these circumstances, the lack of accessible, affordable, timely medical services jeopardized severely the quality of care, if not the vital prognostic for the most vulnerable beneficiaries. In most cases it was difficult to retrieve information on the outcome of the referral, diagnosis, treatment, and therefore the HBCF had difficulties in ensuring a proper follow up.

In Kapelebyong, the project enrolled 5 clients under a free government ARV scheme, implemented in partnership with Uganda Cares. One of the beneficiaries was found to have CD4 cell count of 01. The project is collaborating with the Soroti Regional referral hospital which is one hour and thirty minutes away from the project site for free treatment of opportunistic infections. For example 122 referrals were made during the second quarter. The project vehicle ensures the transportation of clients. The branch has, through its reporting expressed some concern that the access to the vehicle at times has been limited as the car has been used for relief operations as well.

In Kampala South, the project managed to enrol 20 project beneficiaries into a free ARV scheme in partnership with TASO and Mildmay International.

2.16.1 Recommendations

I. Access to proper medical care to be properly re-assessed and reinforced.

II. Referral forms may be beefed up by including the feedback /Diagnosis & treatment, follow up actions to be taken by HBCF.

III. It is imperative now to initiate treatment literacy for volunteers and treatment preparedness for the community.

IV. The URCS may consider establishing more formal contractual agreements with DDHS services and other partners to guarantee proper follow up of clients enrolled in ARV schemes and advocate for better access to medical care.

Branch Capacity Building

In assessing the roles and capacity building efforts at different levels, we have primarily focussed on activities that are linked, to some extent, to the Home Based Care programme and projects.

3.1 URCS Headquarter

At the URCS Headquarters the main stakeholder with regards to the follow-up of the HBC program is the Health Department. The main positions involved are Senior Health Coordinator, Health Coordinator and Assistant HIV/AIDS Coordinator. The Deputy Secretary General is the head of programmes and operations and is through this position also involved both in the overall management of the Home Based Care Program and in external representation and coordination, i.e. as representative of the URCS in the meetings led by Uganda Aids Coordination Office. The Health Coordinator is the budget holder and responsible for the HIV/AIDS programs. Furthermore, he represents the URCS in the NGO Forum, which is briefly described below. The Assistant HIV/AIDS Coordinator assists the Health Coordinator in the follow-up and implementation of the programme. The URCS HQ also has a volunteer, who is living with HIV/AIDS, and he has been a key person contributing to the development and monitoring of the Home Based Care program.

3.2 Branch & project level

Both of the branches consider the Home Based Care projects to have contributed significantly to the strengthening of the branch. Important indicators, which have been mentioned, are the increased number of members and trained volunteers as well as the contribution in terms of assets. The latter has been most important in the Soroti branch, as the main asset is yet to materialise in the Kampala South Branch. Another very important

indicator is the perception among people in the targeted areas that the URCS is a community-based organisation targeting the most vulnerable people within their communities. Both branches see the projects as very important for building a positive image of the Red Cross in the targeted areas and this perception is supported through the feedback from the community and from the external stakeholders.

3.2.1 Staffing and roles

The Soroti/Katakwi and Kampala South branches both have a board consisting of 13 persons including two representatives of the youth and women, the Branch Field Coordinator, Assistant Branch Field Coordinator and Project Coordinator for the HBC project.

For each of the two projects a Project Officer is the main officer responsible for the follow-up of the Home Based Care project. The Project Coordinator in Soroti is a trained nurse and has been in this position since the start of the project in 2002. The Project Coordinator in Kampala South is a trained social worker and has been in this position for two months. Before this, she was a part of the project as Home Care Facilitator.

The branch board in the Soroti branch visits the project on a quarterly basis, as a minimum, to monitor the activities. The aim of the visits is first of all to meet the beneficiaries. One of the Board members is a professional counsellor, who provides guidance to the project staff and volunteers. The board was involved in the process of designing the project, and they make the final decision about issues of major importance for the project. The Kampala South board also visits the project area every quarter, as a part of the quarterly planning exercise to talk to the Home Care Facilitators and the beneficiaries.

Important roles of the Branch Field Coordinator in the two branches are to support, supervise and monitor all the activities of the branch. The background and level of experience of the Project Officers seem to be important with regards to the division of roles between Branch Field Coordinator and Project Officer. The Project Officer in the Soroti Branch seems to operate far more independently in the day-to-day management of the project and as representative of the project externally.

The Project Officer has got a very central role in the development and monitoring of project activities and in the interaction with external stakeholders. It is therefore crucial for the success and progress of the project that the holder of this position is supported and made capable of giving guidance of high quality to the Home Care Facilitators. By investing in building competence at this level, the interaction with external stakeholders could also be strengthened, as this would contribute in the process of positioning the URCS as a serious and competent actor in the fight against HIV/aids in the targeted areas.

According to the working contract of the Project Officers, they are reporting to the Health Coordinator at the URCS HQ. As the Home Based Care program is relatively new, this direct contact could strengthen and improve the streamlining of the program. However, the frequency and character of the contact between the Project Officers and the Health Coordinator do not indicate that this potential is fully exploited. The HQ should make sure that guidelines and information material from the Federation and from other partners at national level are made available and discussed. Moreover, the HQ could facilitate the contact between the Project Officers to ensure that the Home Based Care program is streamlined – not only in structure, but also in quality and content.

There are clear indications of decentralisation of decision making with regards to the implementation of the projects as one can see that different models have been chosen for certain components of the projects, i.e. income generation activities and Project Management Committees. However, the handling of financial resources, procurement etc. seems to be highly centralised. The requisition and procurement procedures seem to create certain barriers against smooth running of the operations, i.e. when a branch considers itself unable to provide a mosquito net to a new client within the first month after the beneficiary was included in the project.

When asked questions regarding the overall financial situation of the programme, none of the branches seem to be particularly well informed. The URCS Headquarter organise an annual planning meeting, where the branches are involved and where working groups are established to discuss plans within their program areas. However, based on our discussions with the branches, we are of the impression that both the HQ and the branches could benefit from an increased dialogue around these issues. Even if the branches have limited capacity with regards to financial management, further involvement

and information sharing could facilitate planning processes and make it more realistic by taking into consideration the capacity of the branch and the financial resources available.

3.2.2 Home Care Facilitators (HCFs)

The project in Kapelebyong has 125 direct beneficiaries, and 25 Home Care Facilitators (HCF) have been trained to be the main contact points with the direct and indirect beneficiaries (family/household). The project in Kampala South has 185 direct beneficiaries and 25 trained HCF (volunteers).

The training and tasks of the Home Care Facilitators have been discussed in the Home Based Care section above.

At the start of the project the volunteers (HCFs) were equipped with a bicycle, but, as discussed in the Home Based Care chapter, no nursing kits are provided (the HCFs in Soroti have been given gloves). The volunteers are facilitated with 5.000 Uganda Shillings to cater for their field expenses and they are supposed to work from 8.30 to 16.30 hours. The HCFs are supposed to work 16 days a month, which brings it to a total of 80.000 Uganda Shillings.

Apart from the day-to-day monitoring and follow-up in the field, there is a monthly meeting between the Project Officer and the HCFs – minutes are made from these meetings.

With regards to turnover, 24 out of 25 Home Care Facilitators in Kapelebyong have been with the project from the start (partly interrupted by the insurgencies in Kapelebyong). In Kampala South 14 out of 25 Home Care Facilitators have been with the project from the start

The perceived capacity and availability of the Home Care Facilitators also seem to differ considerably between the two branches. The Kampala South branch considers the HCFs to be able to increase their workload by 50%, if the financial resources are made available to cover the increase in daily allowance payments - thus increasing the ratio from more than 7 clients per HCF to 11 clients per HCF. The Soroti branch considers the present capacity of the HCFs to be optimal with a ratio of 5 clients per HCF, and consequently they consider recruitment of more volunteers as a prerequisite for further expansion. In the Kampala South branch, the increased visibility has reportedly attracted more professionals

(i.e. nurses) to the branch as volunteers. As these could be very valuable resources for the project, one should allow for a sufficient degree of flexibility with regards to number of hours to be spent with the project.

The Kampala South branch has established a coach system where some of the Home Care Facilitators have been given an additional task of providing guidance and follow-up of other HCFs. As long as these coaches are given the training and guidance they need, this seems like a good way of ensuring that each HCF receive some individual guidance. As the projects expand, this could also be a good way of ensuring a good flow of information to and from the Project Officer.

3.2.4 Other activities

Apart from the Home Based Care project, the Soroti branch is carrying out the following main activities: Social mobilisation (immunisation), blood donor recruitment, disaster preparedness and response, dissemination of Uganda Red Cross Society principles, membership recruitment, tracing, first aid, twinning and a “Youth out of School” program.

The Kampala South branch is carrying out the following main activities: Community Based Health Care Program (CBHC), Disaster Preparedness and response program (DPR), Road Safety Activities and First Aid Training and services.

The integration of the Home Based Care project with other branch activities seems to be relatively limited. Some activities to prevent malaria have been included in the Home Based Care program, and in Kampala South some PHAST-training has been conducted in the project area (Participatory Hygiene and Sanitation Transformation). Furthermore, the increased number of trained volunteers with first aid training (HCFs) is contributing to the preparedness of the branches.

3.2.5 Status membership and volunteers

Membership for home care project branches from 2001 to September 2004:

YEAR	SOROTI	KAMPALA SOUTH
2001	68	119
2002	277	364

2003	395	284
2004-sept	233	307

The development within membership recruitment does support the statement by the branch that the Home Based Care program did contribute to an increased number of members.

3.2.6 Capacity in terms of hardware

The Soroti Branch office is located in Soroti town in a branch building partly financed with HBC project funds and partly through the twinning cooperation with a Swedish Red Cross branch. The building and equipment seems to cover the needs of the branch at present, although the need for a photocopy machine was emphasised by the branch. The following assets are financed with funds from the HBC project: The sub-branch building in Kapelebyong, 50% of the Soroti Branch building, a car, some furniture for the branch building in Soroti and some basic furniture for the branch building in Kapelebyong.

The Kampala South branch is at present located in a rented building with limited space awaiting green light to move into a new building. The property agent created some delays (he is at present in prison) and the purchase has therefore not been finalised. The branch does not have a photocopy machine. The following assets are financed with funds from the HBC project: One motorcycle, one computer and some basic furniture. The computer has been purchased, but yet not delivered from URCS HQ. The reason for this delay is said to be the lacking possibilities of storing the computer safely in the present office. The physical assets are therefore not fully adequate for the smooth running of operations, but it is expected that this situation will improve considerably as soon as the branch moves into the new office. Lacking access to transport for the clients has been mentioned as a challenge by the branch and beneficiaries, as many of the clients at times are either physically or financially unable to access public transport.

3.2.7 Project Management Committees

Both of the branches have established Project Management Committees (PMC). The role of the Project Management Committee is not described in the initial project document. Guidelines describing the roles of the Project Management Committees have been developed at branch level, but the URCS Headquarter has provided some guidance in the process. The Headquarter emphasised that the committee should have a wide

representation from local stakeholders like PLWHAs, the (political) Local Council and the (administrative) Sub-County. The intention is to establish a community mechanism of monitoring the impact of the project.

The Soroti Branch established the PMC in 2003. However, the PMC did not become operational until 2004 due to the insurgencies, which started the day after the PMC, had gone through its first day of training, resulting in a massive movement of the population from the targeted area. The committee contains two health workers representing the two local health centres, a political leader from the Local Council and one representative from each parish, religious leaders from a protestant and a catholic church, as well as a male and a female PLWHA.

The Kampala South Branch has established one PMC in each of the three parishes where the project is located. The PMCs were established at an earlier stage (2003), but was to a limited extent active until quite recently, as it was reactivated in the process of establishing the Income Generation Activities. All the members of the PMCs are clients of the project and each member represents one of the villages of the parish.

The Soroti model has a wide representation from various external stakeholders, while the Kampala South model seems to have more similarities with a user organisation. The consultation with representatives of the clients is of high importance for the success of the project. However, the project has also facilitated the establishment of positive living clubs, and a closer working relationship with these structures could cover the same needs for participation of the target group. Thus, a parallel structure seems somehow confusing. The Soroti model is more in line with the recommendations from the URCS Headquarter and provides a good opportunity to increase the ownership of the project in the community as a whole and to strengthen the network with other stakeholders that are crucial for the success of the project.

3.2.8 Recommendations

1. More resources should be invested in the capacity building for key personnel like the Project Officers. For a start the possibilities of drawing on the resources of key partners should be explored.
2. The Kampala South Branch could benefit from a wider representation in its Project (Management) Committee in line with the recommendations from URCS Headquarters.

3. The URCS Headquarter should make further efforts to involve the branches/Project Officers in discussions regarding the overall financial situation of the programme to create a better foundation for further planning.
4. Documentation of relevance for monitoring the performance of the project should be easily accessible and important decision making processes should be properly documented. The Soroti Branch has a good approach. Dissemination of information and guidance from URCS HQ level should be improved to promote further harmonisation of programme interventions.

4.0 Coordination, partnership, networking

The URCS is represented in various networks and coordination bodies at all levels as described in this section.

4.1 URCS Headquarters

The Deputy Secretary General represents the organisation in the meetings led by Uganda Aids Coordination Office and an important aim of this body is to establish a standard framework among the agencies working to fight HIV/aids. The URCS is also represented by the Health Coordinator in the NGO Forum, where the URCS has a lead role within preventive work supervising other organisations working within this field. Furthermore, the Secretary General represents the URCS, or the person being delegated the responsibility, in the Uganda Aids Commission. The secretariat is a governmental body, but the Commission has a wide representation from Ministries, PHA Networks, National NGOs and International NGOs etc. URCS has also collaborated with the PLWHA Forum to promote a greater Involvement of People living with HIV/Aids in URCS activities.

4.2 Soroti (Katakwi)

Important partners for the Soroti Branch in the implementation of the Home Based Care program are Uganda Cares. The NGO health centre III, located within the project area, is run by a missionary organisation and provides reasonably priced, but not free, services and basic medicines. The public health centre IV is located 5 km away from the project area, but provides free consultations and basic medicines. The capacity is, however, limited and the centre often runs out of medicines.

The possibilities of cooperating with the World Food Program have been explored. The WFP also distributes food in the IDP camp, but they do not seem to have food earmarked

for this target group. The Soroti branch does not seem to have a clear picture of how often and how much food is, and will be, distributed by the WFP (in cooperation with a local partner), but the frequency of the distribution seems to have decreased lately.

4.3 Kampala South

In the implementation of the Home Based Care project, the branch collaborates closely with providers of health services like the Nsambya Home Care, Mildmay, TASO and the Cairo Centre. Furthermore, the Christian Caring Community and Mengo Hospital conducted the first training of Home Care Facilitators. The branch also collaborates with the District Health Team at the DDHS. The main coordinating body in Kampala South is the NGO Forum in Makindye Division.

4.3.1 Comments

Through our discussions with various actors, particularly at the level of MoH and District Health Authorities, it becomes clear that the networking and participation in coordinating bodies at district level is of crucial importance for accessing funds for HIV/aids related programs. It is our impression that the potential for using these arenas to access funds, to increase the knowledge about the activities of other actors, to communicate about URCS activities and to advocate on behalf of the target group is not fully exploited.

Particularly for the clients receiving ARV treatment, a highly coordinated network is crucial. When weak links are identified, i.e. the public health centre in Soroti with inadequate capacity, the URCS needs to be an active advocate to ensure that the beneficiaries receive the best possible treatment.

Similarly, coordination efforts are important to identify uncovered needs and potential partners in areas such as orphan care and water/sanitation, which are examples of topics of high relevance for the beneficiaries of the Home Based Care projects. Both branches are involved in food distribution and material support. As discussed earlier on the organisations involved in food distribution should assess the actual food needs and conduct food distribution in a coordinated manner.

Neither the URCS Headquarters, nor the Kampala branches, seem to participate in the District Aids Committee (DAC). The National Society thus misses an important opportunity for networking in Kampala District.

4.3.2 Recommendation

The URCS should strengthen its networking efforts, particularly at district level, with the aim of promoting the URCS Home Based Care program, improve coordination, advocate on behalf of PLWHAs and access funding. Focussed reports describing URCS activities and its impact should be shared with Health Authorities at district level and national level.

5.0 Reporting, documentation and Sustainability

The URCS HQ has recently developed a monitoring and evaluation framework for the Home Based Care program, which has not yet been implemented at branch level. However, at all levels the approach to documentation of needs, relevant indicators of progress and impact of the program could be further developed. This is closely linked to our comments regarding the lack of baseline survey in the two project areas.

Regarding general data management and documentation, the Soroti branch has a good approach. The data collection from Home Care Facilitators, the documentation of decision-making processes within the board, guidelines for action at project level and reporting seem conscious and easily accessible.

Both branches make monthly, quarterly and annual reports to the URCS Headquarter following a format provided by the Headquarter. However, as repeatedly noted when describing the work of the HBCF there is a need to improve the documentation of medical records and the training process for Home Care Facilitators to effectively make use of detailed records for their work.

The explanation given for the lack of a manual is the delays created at government level to finalise the HBC manual as the URCS will base their manual on the approved government manual.

5.1 Stakeholder Involvement

Our observations and discussions with a wide range of stakeholders at local and central level have shown that the Uganda Red Cross has succeeded in establishing a community-based program. It is encouraging to hear and see that the URCS, through these community based activities, actually is reaching the most vulnerable people within the targeted areas and that these efforts have been noticed also at the central level of the Ugandan society.

Through involvement of PLWHAs at all levels of the Home Based Care program structure (URCS Headquarter, Project Management Committees, among Home Care Facilitators), as well as through the close collaboration with the Positive Living Clubs, there is no doubt that the ownership by the target group is strengthened.

5.2 Sustainability

The financial sustainability of the Soroti branch is at present relatively limited, as the only income, apart from project funds channelled through the URCS HQ, seems to be the membership fees. The HBC project rents office space in the branch office, and this is considered to be an income to cover some of the core costs of the branch. The branch expects to be able to cover 50% of its core costs in 2004. The branch has made plans to construct an additional building next to the branch building to rent it externally. Furthermore, the branch has kept 4.800.000 shillings of the IGA funds allocated to the Home Based Care project to purchase tents and chairs to rent externally (for weddings, meetings and other gatherings).

The financial sustainability of the Kampala South Branch is also limited as the only income, apart from project funds channelled through the URCS HQ, is the membership fees. The branch wishes to start an Internet café, as an income generating activity, when moving to the new premises, but the establishment of such an activity would require external funding.

Both branches have initiated income generation activities to increase financial sustainability at household level (see section on IGAs). If the targeted beneficiaries succeed, this will be an important contribution to make them less dependant on the support, which is now provided by the project. Their success will also make it possible for

other beneficiaries to access this opportunity for earning meagre incomes to meet their basic needs. For example, the aim of the IGAs is to enable PHAs to afford basic treatment, food, mosquito nets, blankets, etc. on their own.

The institutional sustainability is another aspect, which also is of great importance for the longer-term impact of the project. One of the main aims of the project is to build capacity within the households and targeted communities, to assist families and community members in the process of caring for its vulnerable population. As mentioned under community preventive activities, a framework for monitoring and assessing the impact of these efforts should be established.

5.2.3 Recommendation

- URCS head quarters and Branches should be encouraged to start income generating activities to meet some of their recurrent costs
- Branches should explore new networks with partners within the respective districts who are engaged in similar work for collaboration.
- Branches should be encouraged to have Training of Trainers in their respective programme areas with technical support from DDHS rather than relying entirely on volunteers.

6.0 Pending Strategies

6.1 Income Generating Activities (IGAs)

After a long process of discussions, and after hiring consultants to do a study on potential income generating activities, a revolving fund arrangement was established in each of the two branches. The beneficiaries have to identify some kind of business where they would like to invest their loan and, according to the given criteria, they have to pay back their loan within six months. The main difference of the models chosen is that the Soroti Branch is channelling the funds through the Positive Living Clubs while Kampala South Branch chose to establish a more individual arrangement. In both branches the Project Management Committees have an important role in the monitoring process. Based on the available documentation and the discussions with the branches, both branches seem to emphasise the level of vulnerability of the clients when selecting the beneficiaries for the IGAs, the more vulnerable clients should be prioritised. However, the Kampala South

branch seems to focus more on beneficiaries with established businesses, which can be boosted by “injecting” the funds that are given as a loan.

In Soroti the Positive Living Clubs have selected the first clients to benefit from the funds. Each club generally consists of 20 persons and half of these are beneficiaries. Each of the ten clubs has received 500.000 shillings and most of the clubs have decided to distribute these funds to 5 beneficiaries. The clubs are in the process of making bylaws for the management of the funds.

In Kampala South the beneficiaries have been asked to make business plans for their income generating activities. Based on these, the beneficiaries have been selected. An agreement is made between the local leader, Home Care Facilitator and the beneficiary. 50 people have received a loan of Ug. Shillings 100.000, and the Project Officer collects the return payments every Friday.

The review team discussed the arrangement with some of the beneficiaries of the IGAs, and if the experiences of these beneficiaries are representative for the whole group of individuals receiving such loans, the IGAs are a great success. The Soroti Branch describes the 1% interest, as a source of income for the branch in the longer run. One should, however, be aware that if one person/family fails to pay back the 100.000 shillings that has been given as a loan, it would take a long time to compensate for the lost amount with the present interest rate.

Based on the discussions with the involved actors and on the present documentation of the arrangement, there seems to be a need to make guidelines that spell out more clearly the obligations of the beneficiaries, Positive Living Clubs and families. Micro credit organisations working in Uganda should have a lot of experience of relevance for the IGAs. Linking up with such an organisation could help in the process of further developing guidelines and also to provide training to the beneficiaries in managing their savings.

6.1.1 Recommendation

To improve the success rate of the IGAs, the URCS should provide training to the beneficiaries in management of the savings. Linking up with a micro credit partner with relevant experience could help in targeting the training. The IGA arrangement should be closely monitored and the process and activities should be documented to ensure that

good experiences are captured and that failures are not repeated. The collective and individual obligations of the Positive Living Club, family or individual receiving the funds should be spelled out more clearly.

6.2 Orphans and other vulnerable children made vulnerable by HIV/AIDS

The problem of orphans is on the rise in both areas. The total number of orphans was estimated to be over 600 in the Katakwi/Soroti branch. However, unlike Soroti, Kapelebyong lacked organisations targeting support for orphans. There was a general view, both at HQ level and in the two branches that donors are reluctant to sponsor orphan projects. So far, the experience in Kampala is that besides TASO, no other organisation runs programmes targeting orphans in the area.

The URCS does not target OVCs in the HBC project areas - neither in terms of psycho-social support nor in terms of material support. When a client dies, the rest of the family receives nutritional support for three months and after this the support ends.

6.2.1 Recommendations

The fact that the population of orphans in general, and AIDS orphans in particular, is growing at alarming rates calls for concerted effort from MoH and donors to raise required nutritional, care, treatment and other forms of support deemed to be urgent. As it were, the orphan crisis cannot be entirely downloaded onto the URCS projects but collaborate with them.

6.3 Psychosocial support for Home Care facilitators

The psychosocial support includes counselling to make them understand the suffering of the vulnerable and the need to serve them. Most of the training borrows from Christian religious teachings such as the saying 'Serve the vulnerable and God will reward you.' Strategic meetings between HCFs and clients are then organised for information and experience sharing.

Economic rewards are also given in terms of per diem of 5000 Uganda shillings for 16 days, which amounts to 80,000 shillings (about 50 US dollars) and supply of bicycles to facilitate transportation to homes of the beneficiaries.

This support is important because HCFs are responsible for training family members to take care of the clients, positive living clubs that do drama, dance and music, referral

system where the Home Care Facilitators assess the needs during home visits and possibly refer clients to health units, provision of material and nutritional support, recruitment for VCT as well as ongoing counselling. The above roles of Home Care Facilitators are monitored by the Project Officer through home visits.

Joint trainings of HCFs from Kampala South and Soroti have been one way of fostering the sharing of information and challenges. The training focuses on basic counselling, basic nursing care, treatment of opportunistic infections and group dynamics. Training is often collaborated with the Heads of Health Department, HIV/AIDS Coordinators and/or their Assistants. The training manuals used are available at the branch offices for future use. The Soroti branch HCFs have so far gone through three rounds of training.

However there are challenges. For example, HCFs in Soroti observed that they are not equipped with nursing kits.

6.4 Other health components – nutritional and material support, malaria control, safe water and sanitation:

Both the Kampala South and Soroti/Katakwi branches provide material support to clients in the form of mosquito nets, bed sheets, kitchen sets and blankets. However, there are not stocks of materials to be provided to new clients-without considering the delays. The problem partly arises from the considerable encumbrances in the requisition procedures of URCS.

The two branches implement other health programme components including water and sanitation (PHAST-training) and, malaria control activities at community level. However, access to water is limited especially in the camps in Soroti/Katakwi. This remains a very big concern both for clients and the project staff. The access to sanitation facilities is very limited for the target group in Kampala South, creating serious hygienic challenges particularly during the rainy season as access to water and generally food hygienic conditions are critical for the success of the HBC programme, the URCS should advocate among relevant partners and authorities to improve the situation. The URCS should contribute in terms of sensitisation work within the targeted communities.

6.4.1 Recommendation

- The URCS should consider improving on its requisition structure in order to simplify the delivery of supplies to the project areas without jeopardising anti-corruption safe guards. Project Officers are presently not directly in charge of the requisition system and yet they are the overall managers of the implementation process. There is need to striking a good balance between bureaucracy and efficiency.
- Procurement of materials: in order to handle situations whereby a client is taken on Board later/registered as a beneficiary say following death of some beneficiaries, it is good for the material items such as blankets, kitchen sets, mosquito nets which are procured and issued once to beneficiaries, to be procured with some excess number, which remains in the store at the branch to cater for such cases who are registered later (proposed 25% excess)
- There is need to build capacity for HCFs to be involved in disseminating of information on TB, early detection of cases, early seeking of treatment and participate in DOTS.

6.5 Introduction of ART

URCS, given its grassroots advantage over the MoH, could contribute positively towards ART (both in terms of preparedness and monitoring adherence to treatment). Indeed, there is evidence that URCS has already commenced with ART related activities namely ensuring adherence, educating and supporting clients as well as encouraging the establishment of self-support groups. In Soroti for example, it is already planned to introduce ART's in the project areas by including ARV information in their training of PLWHA. The Soroti project noted that they would require 15 additional HCFs to absorb the new 75 beneficiaries of ARVs. However, at the time of this evaluation, it was not clear as to whether these new beneficiaries would have a joint training with earlier beneficiaries or not. ART activities were also in progress in the Kampala South branch with 20 clients so far benefiting from the project.

In the case of the Kampala South branch ARVs are supplied by Mildmay, TASO and Nsambya Home Care. Nsambya Home Care was said to be the cheapest (only 1,500 shillings including transport) in the treatment of opportunistic infections in the Kampala South branch.

Overall, there is concern over the very limited access of ARVs to clients in both project areas. It was particularly observed that the most vulnerable - the very poor for example - cannot access ARVs. As a result, beneficiaries in both the Kampala and Soroti branches have difficulty in accessing ARV drugs.

6.5.1 Recommendation

There is need for ARVs to meet the client demands. Closer collaboration with the MoH and other stakeholders could improve supplies of these much needed drugs as well as improve the capacities to equip the URCS branches with additional information and training to handle any changes and future needs in managing ARTs.

7.0 Financial Analysis

This conforms to the laid out guidelines set by URCS Headquarters.

7.1 Recommendations

- The practice should be maintained and close supervision instituted especially for the IGA's. URCS Headquarters should make further efforts to involve the branches/Project Officers in discussions regarding overall financial situation of the program to create better foundation for further planning.

8.0 Conclusions

The overall performance of the URCS home based care projects reviewed is positive. Locational aspects alone provide excellent opportunities for these projects to reach out to the most vulnerable people living with HIV/AIDS in the country, that is the urban poor (Kampala South) and those in rural areas also negatively affected by instability and displacement (Katakwi/Soroti).

URCSs work is further strengthened by establishing itself as a community based organisation that is not entirely relief oriented. This was recorded as a very postive development with regard to delivering on the project objectives. That way, it has been possible to involve the PLWHA at all levels of the program (GIPA principles in action). It has also enhanced the commitment of staff and partners at all levels (Headquarter staff, branch board, branch staff, project officers and volunteers). It has further ensured that URCS programs are in line with the global and national policies and strategies for implementing HIV/AIDS management programs.

However, much as the project is doing a commendable job there remains some limitations that could be addressed by the URCS Management in order to consolidate their services even further. These are summarised as follows.

There is need to improve communication, networking and collaborative efforts at all levels in a bid to promote URCS Home Based Care Program, advocate on behalf of PLWHA and for resource mobilisation. For example, the Kampala South branch could benefit from wider representation on its Project Management Committee.

More resources should be invested in capacity building especially for the project officers (in areas such as HIV/AIDS information, education and communication and basic nursing skills, for example) and for a start the possibility of drawing on the resources of key partners could be explored. Resources should particularly be channelled to improve the documentation practice of all relevant project documents for monitoring performance of clients by encouraging good documentation and storage. Much effort should focus on improving the Home-Visiting Form to better categorize clients according to their conditions especially by incorporating a check list that captures the patient's situation and needs (e.g. medical and socioeconomic physical and emotional conditions). Improving the quality of this Home Visit Form will make it possible in future to obtain focused information and accurately measure the quality of care provided by HBCF. Alongside this, it is imperative now to initiate treatment literacy for volunteers and treatment preparedness for the community in light of management of opportunistic infections and ARV scale up for PLWHA.

Likewise, to improve the success rate of the IGAs, the URCS should provide training to the beneficiaries in the generation and management of savings. Promoting successful IGAs through publicity and bonuses could provide incentives for improving on the scheme.

Additional psycho-emotional support to HBCF should be emphasized in a more structured and organized manner to target all volunteers.

In order to guarantee that the HBCF trained are competent, URCS should provide course curriculum, training manuals and topical handouts for participants(in local languages) to

the project officers using as much as possible case studies within the project areas. It is also urgent to equip HBCF with nursing kits, torch, boots, and umbrella to improve conditions of work. Additionally, secondary care takers should also obtain the basic nursing equipment to ensure proper nursing care in absence of HBCF.

The program for positive living clubs should be further structured and developed more so by encouraging them to network with the PLWHA Forum. Research is another way of enriching project linkages by continuously learning from clients and their environment. KAP studies should be carried out and appropriate local IEC messages developed for targeted groups. In order to measure the behavior change impact of the projects at household and community levels, it's imperative that baseline surveys be carried out.

Considering the fact that URCS Home Based Care Project areas are already involved in ARV drug initiatives, it is recommended that URCS explores its comparative advantage in the provision of ARVs to the rural communities and starts planning for such implementation in a phased manner.

Finally, considering the negative effects of insurgency and cattle rustling on the social structures and economic livelihoods of communities and resultant increase in HIV sero - positivity of up to 23% in the Soroti/Katawki project area, the role of URCS in community preventive efforts in the area is still big. It is therefore recommended that the HBC Project of URCS be continued, consolidating gains attained while exploring modalities for expansion. If all the above recommendations are implemented, we have no doubt that this will be one of the best HBC Programs that would be ready for scale up.

8.1 Summary of major recommendations

- Redesign URCS Branch IEC strategies to ensure that relevant messages are developed in local languages for different target groups to be based on KAPB studies on misconceptions, attitudes and practices.
- There is need to integrate other preventive health components at community levels, that sanitation, malaria, and TB.
- The URCS should strengthen its networking efforts particularly at district level with the aim of promoting the project, improve co-ordination, advocate on behalf of PLWHAs and access funding.

- More resources should be invested in capacity building for key personnel and important decision-making processes of the URCS should be properly documented and made accessible for monitoring the performance of the project.
- URCS head quarters and branches should be encouraged to start income-generating activities for sustainability. URCS should also be encouraged to have TOT's in their respective programme areas as a way of enhancing sustainability.
- The fact that the population of orphans in general and that of AIDS orphans in particular is growing at an alarming rate calls upon MoH and donors to raise required nutrition, care, treatment and other forms of support deemed to be urgent.
- The URCS should consider improving on its requisition structure in order to simplify the delivery of supplies to the project areas without jeopardizing its anti-corruption safeguards.
- Stocks of additional materials (proposing an extra 25%) should be provided to cater for unforeseen demands.
- There is need to build the capacity of HCFs for their involvement in dissemination of information on TB, early detection of cases, early seeking of treatment, participation in DOTS.
- There is need to build capacity of Positive Living Clubs in identification of essential, cheap and accessible foodstuffs like fruits, vegetables and herbs to PLHWA.
- URCS head quarters should provide more guidance to branch and project officers on HBCF identification as volunteers legally bound to the URCS within the project areas.
- URCS should consider developing a training curriculum for Home Based Care Facilitators such that those who undergo training are competent.
- URCS should develop a standard criteria for identifying clients for support.
- It is urgent that HBCF's are equipped with home based care nursing kits; torch, boots, umbrella's, as well as, a standard home visits monitoring form which properly categorises clients according to their conditions e.g. bed ridden, confined at home, ill but mobile, not too ill and mobile. This form should be in form of a checklist to appreciate the patient's situation and needs as well as to be able to measure the quality of care offered.
- Secondary care takers should have basic nursing equipment to ensure proper nursing care.

- URCS in collaboration with other partners should explore ways of acquiring additional nutritional supplements for the beneficiaries.
- The URCS head quarters should make further efforts to involve the branches/Project Officers in discussions regarding the overall financial situation of the programme to create better foundation for further planning.
- To improve the success rate of the IGAs, the URCS should provide training to the beneficiaries in management of savings by linking up with a micro credit partners with relevant experience to help in the training. The IGAs arrangement should be closely monitored, documented for continuous streamlining.
- URCS should ensure that the ARV supplies in project areas meet client demands.