Comprehensive Care

of People affected by HIV/AIDS

in Uganda

Report of a Field Study in Uganda
on behalf of CEBEMO

Uganda, May - June 1994 **Dr. Carla Otterstedt**

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List of Abbreviations

ACAP	Aber Community AIDS Project
ACYC	AIDS Challenge Youth Club, TASO, Kampala
AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical Research Foundation
CHW	Community Health Worker
HIV	Human Immunodeficiency Virus
MHBC	Mobile home-based Care, Nsambya Hospital, Kampala
NGO	Non-Governmental Organisation
PWA	People with AIDS
STD	Sexual transmitted Diseases
TASO	The AIDS Support Organisation, Kampala
TB	Tuberculosis
TBA	Traditional Birth Attendant
UCMB	Uganda Catholic Medical Bureau, Kampala
UNICEF	United Nations Children's Fund

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1. Introduction

Uganda has been weakened by its short history, especially by the political and economic problems associated with it. The pandemic HIV virus and the subsequent spread of AIDS has weakened the society, especially its population and its social structures. In particular, the generation important to the economy, those aged between 18 and 45, is especially affected by AIDS has very limited on contribution to the labour market. An increasing number of traditional structures disintegrates after an HIV infection becomes known, and as a result, family members become social outcasts. In some areas where the AIDS mortality rate is particularly high (e.g. Rakai area in the south-west) the family and extended family unit is solves due to the overload carried by its members in the care of orphans and the aged. These structural changes do not only affect the care of the sick and orphans, but also reduce collective and individual in coming to terms acceptance of suffering and death.

Facing the limits in prevention and care of HIV/AIDS, counselling means to look for those who are already infected or sick by HIV/AIDS, as well as for those who are affected by HIV/AIDS e.g. as a family member. Comprehensive Care of people with HIV/AIDS means to give support for those who are in an important stage of their life: to life with the knowledge of becoming more ill and going to die. In case of counselling HIV-infected persons there will be the chance to motivate them for "living positively", to take the time for enjoy and arrange things of life. But in the most African countries people will get the diagnose HIV/AIDS very late, if at all. In this situation counselling of AIDS patients means often counselling of a terminally ill or dying patient.
Counselling of terminally ill and dying patients demands a holistic approach in answering the different needs of the patient, as well as of these of his family: palliative medical care, nursing, counselling (also for the bereaves). The social support (e.g. material assistance) should be also included, especially in areas like Uganda, where economic resources are very poor.

In case of pandemic of HIV/AIDS like in Uganda, where the society and the economic situation is affected by a decimated population, it will be also needed to look forward to build up a new generation with a strong cultural and social identity.
As HIV/AIDS cannot be stopped by prevention and education entirely, it will be necessary to give this new generation an idea to live with the present of HIV/AIDS epidemic, to accept the risk and prevent a transmission of the virus, and to have experiences of becoming a social community and a strong cultural society.

2. Methodology

2.1 Selection

In Uganda, the selection of projects to be visited has in the first place been directed towards these in which support groups are involved in care and counselling of HIV/AIDS patients and their families.
The objective was to compare the given situation and the visions of counselling programs in urban and rural areas as well as to discuss holistic programs for comprehensive care.

2.2 Data collection

Information has been collected through numerous individual and group interviews and observations at the level of Non Governmental Organisations (NGOs), Self-help groups, Churches and Funding Agencies.
Field of evaluation were the districts of Rakai, Masaka, Lira, Apac, Gulu, Kitgum, as well the rural and urban areas around Kampala and Jinja.

Priority topics of interchange with support givers were:
- Field of work
- Field experiences
- Effects of work
- Main problems and needs
- Vision of work in future
- Discussion of feasible alternatives

Furthermore policy papers and other related studies and reports have been studied (see Bibliography).

2.3 Terminology

Comprehensive Care
means Care and Counselling in a holistic way.
Due to physical, psychical and social factors in the field of living with HIV/AIDS,
different types of Care and Counselling will be necessary:[1]

- Health Care
- Education
- Psycho-Social-Support and Counselling
- Material Assistance
- Palliative Medical Care
- Home Care Service
- Training and Supervision of the Staff

[1] See also 5.

3. Social Structures and Coping Mechanism in the Past and Today

The care of the sick and dying[2], as well as the care of those left behind (spouses, orphans[3]) comprises a traditional part of the social community. In all cultures, there are various forms of social care for members of the community who are weaker than others. It appears to be a human need to help others. These social behavioural patterns change with the development of a society and the change of its corresponding social behaviour customs.
Social structures such as the family and the extended family unit which has the role of protecting and supporting the unit, can be forced to disintegrate during economically weak times (rural exodus, decentralisation of the family unit). The loss of traditional family life and its psycho-social function can consequently change the social behaviour of the society (sexual behaviour, multiple partner changing[4]). Through the lack of social support by the community, situations involving economic and health needs, demands and outside care ensure.

The political past and the weakened economy that result from it, are, apart from individual ideas of how to live own life, one of the main reasons for the decentralisation of the traditional family and extended family unit in Uganda. Other reasons among other things are poverty and migration.

Present sexual behaviour, dominated by frequent change of partners before marriage and also the continuation of this practice by the husbands, is cause for the spread of the HIV virus in Uganda. While the women look after their children and their shamba[5] in rural areas, many men are relied upon to look for work in the cities[6]. After becoming infected by HIV, the men return to their villages and are cared for by the women. These women, frequently infected themselves through their husband, rely on the help of their relatives so that they can look after their sick or dying men, children[7] (often prenatal HIV infected) and work the fields. Since other families in the region find themselves in the same situation, the capacity to provide sufficient aid is often limited. Relatives decline to help or to take on orphans because they themselves have reached their limits.

Sexual behaviour in Uganda is presently influenced by several factors:
- common opinion: expressing love means sexual intercourse
  -> especially adolescence are influence by this believe
- prevention by condoms is well-known, but not how to use them properly
  -> wrong use of condoms, pregnancy, transmission of STD or HIV.
- alcohol consumption
  -> loss of control of own behaviour leading rap and unfaithfullness
- social and economical situation
  -> prostitution as a kind of bread winning, especially for widows and orphans
- living situation
  -> living with parents in one room, leading to copy of their (sexual) behaviour

Correlation exist between social and economical situation and the individual behaviour. In case of poverty and homeless, often women and children "accept" to sell their body.
Men still contact prostitutes. Despite of education, if these men are influenced by alcohol, often disregard their own knowledge about prevention. Due to high rate of alcoholic men in Uganda, general depend role of women[8], rape and sexual abuse is common.

Behavioural Change, especially of sexual behaviour, means to influence the social behaviour and living situation of the people. TV and western movies have a great influence of the people, but shown mostly the behaviour of extreme characters (rich/poor, evil/good ones) without motivating the own fantasy. Advertising exist mostly for cigarettes. But to advertise commercially for a positive change of behaviour, could be a challenge for the future. Traditionally books are not very popular and most Ugandan people have no access to mass media, like TV or newspaper. Even the radio transmission is available on the limited scale. Behavioural change, illustrated by short comic-strips could be additional method in education and counselling.

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[2] see Glossary *death, marriage, philosophy, spiritual life*.
[3] see Glossary *orphans*.
[4] see Glossary *anomie, behaviour*.
[5] := (Kiswahili) small piece of land for private farming
[6] see Glossary *family*.
[7] see Glossary *children, immortality*.
[8] see Glossary *women.*

Due to disaperance of generation of the elders, trained in traditional ways of counselling[9], there is a growing need of professional and para-professional counselling. Apart that, there are also other reasons which provide the starting points for a care and counselling programme[10]:

1. Fear of being infected by HIV
2. Fear of being stigmatised and socially outcast[11]
3. Problem of confrontation with illness, dying and death[12]
4. Fear of taking on too much responsibility (maintenance for having to bring up additional orphans)

[9] see Glossary *counselling*.
[10] Consequences for counselling, see Annex II.
[11] see Glossary *health, society*.
[12] see Glossary *dying*.

4. Care and Counselling of People affected by HIV/AIDS in Uganda

The follow-up describes the specific needs of terminally ill or dying people and their relatives, as well as the needs of the staff to cope with the issues to take care and counsel these clients. The description is related to the present support services of visited NGOs in Uganda.

4.1 Health Care

Health Care is provided as a stationary service in hospitals, as well as in AIDS Clinics and Home Care Services[13], included Mobile Units.
The well functional health care and treatment of AIDS-patients will be part of comprehensive care and an important argument for people infected by HIV to get in contact with the different services (e.g. counselling, home care). The effects of a appropriate treatment will have also increase chances of social acceptance of people affected by HIV/AIDS. "Since treatment and counselling, that sort of stigmatisation has gone."(Kitovu-Hospital, Masaka-Rakai) [14]

Hospital
Stationary medical care of people infected by HIV means generally, in relation to their low immunsystem and therefore extraordinary complications, a longer stay than other patients and more intensive nursery.
"Up to 70% of medical beds are occupied by patients with AIDS related illnesses, patients who are HIV positive have on average a longer stay in hospital following surgery, or delivery."(Nsambya-Hospital, Kampala)[15]

Weak and without work, patients often have no money to pay for the medical treatment. Financial resources of the hospitals get regularly exhausted by giving support to those who can not pay the bill. "Due to the rapid increase in the amount of the bills and the numbers not paying, this grant has been exhausted sooner than anticipated." (Kitovu-Hospital, Masaka-Rakai)[16] Free National Health Care seems not always accepted by patients due to the general belief that best health care have to be expensive.

As drugs are often given free, alternatives and conditions have to be found. "Extra drugs are budgeted for, and supplies are often short, as once people begin to show sights of AIDS, they often need several or more drugs. Recently the Patient Care and Ethical Sub-Committee have drawn up guide lines in the form of flow charts to guide people in the treatment of opportunistic infections - using selected essential drugs. These guidelines endeavour to keep prescriptions to not more than four drugs." (Nsambya-Hospital)[17]

[13] See 5.6
[14] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.36
[15] in: AIDS integrated activities at St.Francis Hospital Nsambya and Home Care Service, Annual Report 1993, p.1.
[16] in "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions", Kitovu Hospital, Pastoral Care and Counselling, Sr.Kay,MMM, (1994), p.24.
[17] in: AIDS integrated activities at St.Francis Hospital Nsambya and Home Care Service, Annual Report 1993, p.2.

HIV/AIDS related Diseases
In case of the low immunsystem, people infected by HIV often also affected by other diseases, like STD, TB and cancer.

In Kampala 10% of those, who are infected by HIV also affected by STD. "Many people are coming in for a HIV test rather than coming in to report an STD. Their illness may often be a combination of both HIV and STD. It is estimated that one in ten people who are HIV+ also have an STD."(Nsambya-Hospital, Kampala)[18]

Nearla under control in the past rate of TB patients in time of HIV/AIDS is raising again."Before HIV/AIDS, TB was mainly limited to cattle keepers. Now, however TB is on the increase."[19]
TB is developing atypical symptoms and certain treatment can provoke serious reaction.
TB is often the first disease that people infected by HIV will get. And therefore also called a "disease defining".
The German Leprosy Relief Association in Uganda also recognised the causal relation between the rise of HIV/AIDS-rate and TB. " 50% of the TB-patients are HIV positive."[20] Due to the fall of cases of Leprosy, the German Leprosy Relief Association now engage themselves in supporting the TB-patients. Their engagement, to support hospitals and clinics with drugs, includes indirectly also those AIDS-patients, which are already infected by TB.
In a study about the relationship between HIV and other diseases in the south Ugandan Rakai District, a HIV-Infection rate of 70 % among TB patients were found.[21]

Another HIV/AIDS related disease is a cancer. The AIDS related cancer (Karposi's sarcoma) now accounts for practically all cancers in males and 23% in females. In a study (1991) of 30,000 AIDS patients carried out in the Cancer Institute of Mulago Hospital, Kampala, 2.3% had Karposi's sarcoma.
The head of Hospice Uganda recognised the challenge in doing support also for those patients who are infected by HIV. "This will affect the profile of the patients we are looking after."[22] and "We expect that 75% of our patients in Hospice Uganda will suffer from AIDS as well as from cancer."[23]

4.2 Education

The Uganda Catholic Medical Bureau has developed a three-year Operational Plan with following specific objectives for the program of *AIDS Control & Prevention*[24] concerning *Counselling, Education* and *Behavioural Change*. The implementation of the education program are seen as task on both, national and grass root level.

Education
"To develop and implement educational programs that will strengthen community coping mechanism at diocesan level and acceptance of AIDS and will facilitate in the development of grass root AIDS Committees."[25]

Activities
- Giving relevant information on AIDS through Seminars and workshops
- Continue with ongoing AIDS Education

Expected Results
- Appropriate Information giving
- Country wide spread of AIDS Education

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[18] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.25.
[19] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.37.
[20] in: "Das Deutsche Aussätzigen Hilfswerk - German Leprosy Relief Association - in Uganda", Fakten-Hintergründe-Zahlen, p.2. "Heute werden ca. 30.000 TB-Kranke in Uganda behandelt. Man geht jedoch davon aus, daß nur 20-25% aller TB-Fälle bekannt werden."
[21] Flint, J. (1994), p.108.
[22] Merriman, A. (1993)2, p.4f.
[23] Merriman, A. (1993)1, p.24.
[24] in: Uganda Episcopal Conference, Uganda Catholic Medical Bureau, 3-year Operational Plan (1994-1996), p.33-34
[25] sic, p.33 + 37

In the meantime at the diocesan level a number of educational activities are taking place, like that of the Aber Community AIDS Project (ACAP) executed by the young professional team of Pope John's 23rd-Hospital, in rural Apac-District in the North. "The aim was to create HIV/AIDS awareness, methods of transmission, prevention and control, promote behavioural change, give a positive out-look to people infected and affected with AIDS. Most of the other community members have also received AIDS information and education through songs, drama and plays performed by local groups and many talks given by the manager and staff to a variety of audiences. Educational stories were developed for different target groups using flashcard illustrations." [26]

The team of ACAP had recognised the importance of effective methods in education and had discussed their experiences and the effects with/of educational methods from western and African culture. "ACAP workers have recognise the limited effectiveness of western techniques and messages in AIDS education and counselling. During the training of volunteers, efforts have been made to understand AIDS, sex, marriage and health through Ugandan eyes. Role play, drama, story telling and communications within the extended family have all been emphasised."[27]

4.3 Psycho-Social Support and Counselling

Due to the long-time development of this disease psycho-Social Support and Counselling of people affected by HIV and ADS means usually a long-time companionship among counsellor, patient and family. "HIV/AIDS is an ongoing dialogue and relationship between client or patient and counsellor, with the aims of: (1) preventing transmission of HIV infection and (2) providing psycho social support to those already affected."[28] "Counselling attempts to help people define for themselves the nature of the problems they face and make realistic decisions about what they can do to reduce the impact of those problems on themselves and their family and friends."[29] Counselling should help clarify and address problems. Counselling should provide information on available resources. And Counselling should help the client to adopt a realistic approach to changing life-style. Counselling should motivate and facilitate decision-making: "People are more motivated to change when they feel they have control over their lives and their decisions, and when their life-skills, self-respect, and confidence are increased. (...) Maintaining status within the community is equally likely to be a source of motivation." [30]

Who is HIV/AIDS counselling for? [31]

1. People worried that they might be infected with HIV.
2. People considering being tested for HIV.
3. People who have been tested for HIV (with or without infection).[32]
4. People who choose not to be tested despite past or current risk behaviour.
5. People who are unaware of the risks for HIV involved in specific behaviour in which they have previously, or are currently, engaged.
6. People with AIDS or other disease related to their HIV infection.
7. People experiencing difficulties with employment, housing, finances, family, etc., as a result of HIV infection.
8. The family and friends of people who are infected with HIV.
9. Health workers and others who come into regular contact with people infected with HIV.

[26] in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.5.

[27] in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.9.

[28] WHO (1990:10)

[29] WHO (1990:10)

[30] WHO (1990:20)

[31] WHO (1990:11)

[32] In expectation of take part on material assistance projects, a negative result could be disappointment in case of poverty and hopeless situation: e.g. window with twelve children, which lost her shamba by the man's family after the dead of her husband.

To be effective, "Counselling should be an integral part of all HIV testing, screening, and health care programmes."[33] "This demand for an improved interaction between patients and health care provider is providing new opportunities for the empowerment of patients, the mobilisation of communities around issues of quality of life during illness, and the importance of psycho social support in disease prevention."[34]

In Uganda counsellors prioritised social impacts as follows:[35]
1. orphans
2. widows (maltreatment of) and widowers
3. stigmatisation
4. adverse effects on labour markets
5. death of one's contemporaries

Counsellors usually carry out pre-test counselling, post-testing and ongoing supportive counselling.
Counselling service e.g. in Nsambya-Hospital, Kampala are:[36]
- Home Care department daily
- Special AIDS Clinics which are held every Tuesday for new patients and Wednesday for return visits
- On the Wards for in-patients
- At Home for the patients and family members

Because of ignorance and fear of will making, there is still a need of legal service, given to clients in need every Wednesday in Nsambya-Hospital, Kampala at the project premises.
In annex VIII, a counsellor of Nsambya Hospital describes his experience and some dilemmas when dealing with clients.

Terminally ill and dying patient

Caused by limited financial resources, people will often recognise their infection by HIV not before first symptoms of AIDS or other diseases, like cancer or TB. Even than patients will be not routinely tested, because of high price of the test kits.(Mulago-Hospital, Kampala)[37] "The majority of our clients come to the hospital because they are already significantly ill. This places a special burden on the counsellor to deal with the issues around dying."[38] Counselling of these patients means to look for their needs as a terminally ill or dying patient. In case of this situation, doing care and counselling in an holistic approach will be the optimum of giving support. In case of terminally ill and dying patients, already worked palliative medical care assumed, the counsellor has to give a tremendous job in being open and sensitive for the needs of the patient. "We have observed in the counsellors that there is a growing awareness that these skills offer hope and comfort in spite of the lack of the usual medical interventions."[39]

Family

Especially medical support structures, like home based care demands also psycho-social support of the whole family. "Home based care without family support is not management - it is neglect."[40] The aims of talking with the people, who take care of the patient, "is to ensure that the patient receives appropriate care and also that the family feels they are not alone."[41] Looking for ways to exploit this established system: "Family counsellors can do

[33] WHO (1990:9)

[34] Carballo, M.; Miller,D. (1989), p.117

[35] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.42.

[36] in: AIDS integrated activities at St.Francis Hospital Nsambya and Home Care Service, Annual Report 1993, p.3.

[37] The Kampala based AIDS Clinic "Mulago Hospital does not systematically test inpatients for HIV infection. However desirable this might be, there are simply not enough HIV testing kits available. Diagnosis is usually done on the basis of a physical examination and clinical history." (Hampton, J. (1991), p.17f)

[38] Ego, M.L.; Moran M. (1993), p.90

[39] Ego, M.; Moran, M. (1993), p.90

[40] Chaava,T. (1990), p.84

[41] Chaava,T. (1990), p.84

a tremendous job. They do need, however, to learn to give accurate information - a need which our trained counsellors can address."[42]
Counselling of members of the family, as well support given neighbours or friends, can be help for coping with their own emotions and reducing fears and stigmatising. "Help may be needed to deal with guilt, depression and family discord, and in this time of crisis there is the possibility of resolving old problems and finding reconciliation's that greatly strengthen the family group."[43]
TASO prepare a Counselling and Support Project for Children. Methods will be adapted by western children counselling programmes, which may follow a cultural different way to those who are needed in African cultures.[44]

Meeting Points and Day Care Centres
AIDS Centres with Counselling Services often offer special Meeting Points, like Day Care Centres, where people affected by HIV/AIDS get chance for interchange their experiences in living with HIV/AIDS.
Special meetings for relatives and bereaves are envisaged or already started by TASO[45] and in Kamwokya, Kampala.[46]

TASO, Kampala works on realising ...
- AIDS Challenge Youth Club (pilot project since 1993)
  a meeting point for the adolescence
- Children Club
  a meeting point for pupils of secondary school

The Youth Club is founded by some AIDS-orphans between 16 and 18 years old, which interchange their emotional experiences parents dying by AIDS. The equivalent for younger children seems to fail in transporting the children from school to the meeting point.
An adoption of western methods in counselling of children seems not being motivated by the TASO counsellor-trainers themself, which can not see a priority need of different methods in counselling people in different ages. It seems that in TASO counsellor training centre and orphan's programme is still no discussion about the role of cultural aspects in counselling.

In the rural area of Apac-District, the Anti AIDS-Club were established by Aber Community AIDS Project in four schools. The idea is "to attempt to increase the interest and influence the attitudes and behaviour of students and their peers through their involvement in AIDS-related activities."[47]

Medical Professionals[48]
"I used to see people with AIDS, but before coming into contact with TASO I didn't know what to do. I didn't know what to tell them because I felt I couldn't do much for them. So we were hiding the diagnosis. It was too painful to tell them. But when I heard about positive living with AIDS, I saw there was something that could be done, for example, counselling people before and after the HIV test."[49]
There is a need to inform the medical staff about the possibilities of pastoral care and counselling and train them in simple skills of counselling. "At first there was a great resistance from many of the staff to this service (Pastoral Care and Counselling); they did not want patients to know their diagnosis nor did they want to have to

[42] Kalibala,S.; Kaleeba,N. (1989), p.174
[43] Saunders, C. (1984), p.51
[44] Counselling of children in western countries means to give children space to express their feelings by playing with toys and doing role games. Children in african cultures traditionally are not use to play with toys, some of them never had a doll or some other toys. In this case to adapt western counselling methods could mean to overload the children with new impressions.
[45] The AIDS Support Organisation (TASO) was founded by a group of volunteers in late 1987.
Since the establishment of TASO, running costs and capital expenditure were paid by the British organisations Action Aid and World in Need. Drugs have been donated by WHO and other international health organisations.
[46] See also 6.3.1.
[47] in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.5.
[48] See also 5.7.
[49] Dr. Sam Kalibala, AIDS clinic, Masaka, in: Hampton, J. (1991), p.10.

deal with the emotional reactions. (...) It had been difficult to prepare patients for death when no one would tell them that they had AIDS and were dying." [50]

Similar situation was observed in a Mission-Hospital in north-east of Uganda, which gives the free service of regularly HIV-testing and having several in-patients on special TB- and AIDS-wards. The matron herself was afraid to talk openly in front of the staff about the existence of AIDS-patients. She explained whispering, that there might be a fear by the staff of getting in contact with AIDS-patients.
The recognisable suppression and fear of expressing themselves in front of superior and collegeaus, can be reason for inappropriate coping with emotions and working-conditions. And also a quick all-time-prepared-spiritual-answer by missionaries can be block the individual needed time to find an answer themselves.

Statistics on staff loss due to AIDS are generally not available or confidential. Nsambya-Hospital reported on average about losing one staff member per month. To cope with high rate of people affected by HIV/AIDS in the daily field of work, included the collegeaus, is one of the emotional challenges staff being confronted. Besides coping with emotions of leave-taking, often the staff has to carry on the work of ill and weak collegeaus. "Staff members who are infected, although they wish to continue working in order to keep their income, do not have the energy to do full time duty." (Kitovu-Hospital)[51]

Cultural Aspect in Counselling of Behavioural Change
An addition of discussing cultural methods of education and counselling, the team of ACAP, Aber-Hospital, accept and help themselves by the regional community network in transmitting information about AIDS and behavioural change. "Apac District have a rich tradition of strong inter-personal relationships, oral culture, family and community networks. The community-based approach recognises and build upon these strengths. Information given out by various government departments, politicians and church leaders my be rejected in favour of traditional beliefs; new ideas must be discussed first within the family or community before being accepted or rejected by the elders. Whereas the messages contained in mass media campaigns and the information given by professional workers during their official duties my be doubted, people such as ACAP's volunteers who are giving advice and education in familiar surroundings may be more likely to be trusted. In Uganda, there is no tradition of open discussion about sexual matters," in case of transmission of ideas of behavioural change follows: "this topic may be raised more easily through small group discussions and individual counselling."[52]

"There has been some change in behaviour, but it is difficult to gauge it precisely." (Kitovu Hospital, Masaka-Rakai)[53] The question, if behavioural change worked, seems to be a problem of evaluation. "Staff in the MHBC[54] Team felt that questions as to behavioural change were difficult to answer definitively. They had mixed feelings as to whether behaviour had changed. Whilst some people really had changed, others claimed that they had, even though they had not."(Nsambya Hospital, Kampala)[55] An extensive evaluation will be needed, which consider the cultural situation, as well as include verbal and non-verbal methods of human behaviour. The result of this evaluation will not only be interest for scientific addresses, especially e.g. the counsellors will get another way of feed-back of their engagement and evaluation also can promote development of alternative ways of counselling.

4.4 Material Assistance

There is a close relation between illnesses, like the weakness through long-term-diarrhoea and -fever by AIDS, and unfit to do work, becoming poor and depended by material assistance. Traditionally, the patient and his

[50] sic, p.1+3.
[51] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.39.
[52] in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.9.
[53] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.37.
[54] Mobile Home Based Care in Nsambya Hospital, Kampala.
[55] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.24.

family is supported by his clan, but due to social fear, discrimination and overburden relatives in areas with high prevalence of HIV/AIDS, but patient will be increasingly on help by professionals.

Common reasons asking for material assistance:
- Material assistance is necessary in case of loss the breadwinner, or family support contacts.
- In case of discrimination, often people with AIDS will not allowed to return in their family's home. New place to stay has to be found.
- Elder and helpless patients are sometimes left by their children and relatives. New contact (to neighbours, friends) for giving them basic support must be arrange.
- Grandparents who are looking for the orphans need financial and material assistance for food, clothes and school fees.

In the beginning of HIV/AIDS pandemic, the NGOs tried to support nearly everyone who ask for help. Due to still growing rate of people in need, the limits of financial and material support are already reached. The changed economical situation in western countries implies stagnation, even fall of financial support by funding agencies. Local NGOs, dependent on those funds, will be more and more economise by lower funds. In given situation, NGOs in areas with high prevalence by HIV/AIDS have to define their own limits of giving support. Which clearly means a special psychical challenge for support givers, and also physical demands for people in need:
- to restrict the number of supported people,
- to turn away people in need,
- to support only a limited group of the large number of orphans.

Despite of the knowledge about the raising number of unsupported people affected by HIV/AIDS, the idea of restricted support is necessary to be bale to provide and continue long-term support.
Those, who are supported by NGOs, in relation to their individual financial situation, also get free drugs, financial support (school fees, burial, travelling-cost) or clothes. Basic needs, like food, will be usually given directly by food support, like rice, flour, oil and beans, etc..
Needs exist also in getting material support for take care of patients at home. Bed sheets and other things to do basic hygiene, are often not available, but can be supported with so called "Home Care Kits" by NGOs. The TASO Day Care Centre, Kampala, is an example of well functional co-operation between people affected by HIV/AIDS, still working and those, who need already the aid. "Home care kits are prepared by the clients in the day centres. These consist of a pair of cotton bed sheets, a bar of laundry soap and one metre plastic sheeting."[56]

An example for the social problems by the privileged support of people affected by HIV/AIDS was founded by the misery of a mother from Rakai-District. She asked repeatedly for being diagnosed as a AIDS patient because of getting material assistant like people affected by HIV/AIDS for herself and her children. "From the early days of the department when supplies of food and other items became available, there have been misunderstandings and strong feelings about services being available only for patients with AIDS. As the department grew there was an attempt to prevent it being only for those with AIDS. Some of the ways attempted were the paying of unpaid children's bills regardless of the diagnosis, having counsellors attend ward rounds with the doctors, making counselling available to all patients, taking an old "hospital social cases", social work assessments of patients unable to pay deposits, milk to all TB patients (...) (Kitovu-Hospital, Masaka-Rakai).[57]

Income Generating Project

The general idea of Income Generating Projects are to improve patients social and economic welfare. As the project manager of Aber Community AIDS Project, Dr. Drake Adupa, explains, income generating projects aimed also additional ideas. "The plan was to support the developing of simple community based income generating activities for people with AIDS and their families. This was intended to assist clients earn some income to support themselves, their families and orphans as most of them have lost their earning capacities either through loss of their jobs or weakened ability to engage in consistent productive activities."[58] The psychical effects by working and earning own money, should not underestimate. "There has been some suggestion that

[56]Hampton, J. (1991), p.18f

[57]in "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions", Kitovu Hospital, Pastoral Care and Counselling, Sr.Kay,MMM, (1994), p.3.

[58]in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.3.

income generating projects (...) could act as a "hook" on which people could hang behaviour change in that they give them hope for the future as well as financial assistance."[59]

Advantages of family income generating projects:[60]
1. The individual sees it as his own projects thus total effort is put towards the success.
2. Most are home based projects thud cutting down on expenditure in travel.
3. The clients can work at his own pace according to their physical conditions.
4. It is hard for clients to join into co-operatives because there is difference in the hour put in by the individuals in the project.

"The greatest benefits are that the patient is allowed the dignity to work and provide for the family for as long as possible. Patients who are busy with their projects are more contented, less worried about themselves, their appetite improves, sleep better and they often live longer."[61]

Since 1991, in Nsambya-Hospital, Kampala, 500 small scale income generating projects have been funded. The projects funded ranged from Poultry, Piggery, Farming, Tailoring, Bakery and Mini-projects (Retails). Especially the projects of Poultry and Tailoring are successful (95%) following by Piggery and Bakery (64-67%). The kind of projects corresponded to the facilities and needs of the operation area. In the south of Uganda, in rural areas of Masaka and Rakai District, Income Generating Projects also includes gardens and brick making. Especially brick making seems to be very successful. Kitovu-Hospital registrated a 1:1 relation between contribution from beneficiary and the project themselves.[62]
The projects are combined with the Home Visiting Programme. In Nsambya Hospital, the team visit four new projects per day and do also re-visits to assist clients whenever there will be a problem.

Orphan's Program

As a typical present situation of orphans in areas affected by HIV/AIDS, the following example of orphan's program is given. Food assistance is given by Pope John's 23rd Hospital of Aber, but limited resources only allowed to support orphans below 10 years. "Their number is increasing daily; a total of more than 500 AIDS orphans are presently registered with the project and being assisted with food only. Within our available resources, the project is unable to support them wholly with school fees, clothing, medical care and many others."[63]

Due to own limited financial resources, Nsambya Hospital, Kampala, started an orphan's support project, with cost-sharing-scheme by the financial power of those parents, which could earn money. A part of the earned money is given to a special account, which will be later the financial basis for the orphans. After parent's death, as the relatives usually take properties, the orphans will be supported by the parent's money from the bank.

[59] in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.25

[60] in: AIDS integrated activities at St.Francis Hospital Nsambya and Home Care Service, Annual Report 1993, p.9.

[61] sic

[62] see also A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.35f.

[63] in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.7.

Support of orphans challenges the support givers in a number of ways:
- increasing number of orphans (average 8-12 children per mother)
- often young children and babies
  (because of died parents of age-group with high prevalence by HIV/AIDS, 18-45 years)
- overload relatives and no possibilities of adoption (or separate adoption of sisters and brothers)
- orphans with different experiences of dying parents (war, accident, AIDS, other illness)
- orphans with different religious, cultural background and nationality

8000 orphans are supported by Kitovu-Hospital in Masaka and Rakai District. Due to the low distance to the border to Rwanda, some of the orphans are children of Rwandans refugees[64], which have no relatives in Uganda. After the death of their parents, the children will have no chance to be adopted by relatives or being integrated in their own clan. Some of these orphans, those parents died by HIV/AIDS, get material assistance and school fees will be paid directly to the bank. The income generating project of Kitovu Hospital (Masaka-Rakai) look for funding projects to teach the orphans skills, like home managing, farming, house making[65], crafting and tailoring.

4.5 Palliative Medical Care

"Presenting needs of persons with HIV/AIDS, and incurable disease, challenged the nursing and medical staff in new ways."[66] As already described in 5.3, psychical support and counselling will take an important part in medical support of people infected by HIV or AIDS-patients, including counselling of terminally ill patients and their relatives, as well as supervision of the staff.[67]
In case of terminally ill patients, intensive and sensitive counselling will help the patient to cope with physical and psychical motivated pain. But well functional medical pain and symptom control in terminal care will also be necessary, because a high rate of AIDS patients suffers by pain (e.g. caused by cancer).

In medical support of AIDS patients in Uganda painkillers, like non-opioids (aspirin and paracetamol) usually are available. In fact of strong pain, weak opioids, like codeine will be given. Strong opioide, like morphine, are extremely rare available. Restricted import rates of morphine, directed by the government,[68] might be one reason. Another reason might be rare chances of education and practical experiences in management of pain control.[69]

The head of Hospice Uganda and palliative care specialist, Dr. Anne Merriman, offers training courses in management of pain control for medical professionals. They are well prepared, one trained nurse of TASO AIDS Centre in Mulago explained, but for practising their knowledge, needed opioide are not yet available.

[64] These refugees were arrived in Uganda years before the actual war started and the children of them were born in Uganda.
[65] There are many cases of unfinished houses by early died parents. To finish the house making will be necessary to give the orphans a chance to get a homeplace.
[66] Ego, M.L.; Moran, M. (1993), p.91
[67] see also 5.7.
[68] The goverment of Uganda fears opioide as reason of addiction-culture in future.
[69] See also Doyle,D.; Benton,T.F., Merriman, A. (1990)

5. Level of Care

5.1 Home Care

In countries with low budged financial resources, like Uganda, Home Care is primarily based on voluntarily care by relatives of the patient. Expensive private nursing is not corresponding to the cultural and economical situation in Uganda.
Home Care Service is organised by Mobile Units of hospitals, which offers several services around managing of home care, physical and psychical support of patient and relatives.

Service of Home Care in the meaning of holistic approach usually includes the following service:
1. Symptoms control and Palliative Medical Care
2. Teams (Clinical, Nursing, Inter professional, Home Care)
3. Maximising potential
4. Place of choice
5. Patient and family
6. Bereavement service
7. Management
8. Community
9. Search for meaning

Due to limited capacities of hospitals (no long-term nursing) and stationary Hospice, for patient and relatives home care is the needed alternative. The long-term illness of an AIDS patient often overload the related caretaker and the team of Home Care Service will give not only the patient support, even counsel his relatives. Important tasks of a Home Care Team is the social contact to the whole family, to recognise their needs and to give them psychical and material support as possible. "Home Care has many advantages over hospital care. It enables the counsellor to assess the client's social and economic situation. It also helps to break down or prevent the sense of isolation experienced by many people with HIV and AIDS. Home Care also brings the counsellor into contact with other members of the client's family."[70]

Other reasons for Home Care are:[71]
- hospital is unable to cure a patient
- relatives prefer to take the patient home to die
- patient themselves prefer to die at home

Development of Home Care Engagement in Kitovu Hospital
as example of Home Care Services with long-term experiences and flexibility of development internal structures.
1989 an "AIDS Referral Clinic" has started in Kitovu Hospital, Masaka-Rakai, with the intention to provide integrated care for AIDS patients, which includes services, like medical diagnosis and treatment, counselling, spiritual care and social assistance. "At the start of the clinic, the Mobil Team was still carrying out home care services in the local area. Patients began to avail both services (...). Mobil stopped its service in the local area and Pastoral Care began to try and visit those patients from the clinic who became too weak to attend."[72] 1992 major changes in Home Care/Mobil Unit were referral e.g. to return visits every two weeks instead of weekly, cost sharing, limited food supplies and group counselling.
Group Counselling[73] "was carried out at the Referral Clinic and patients were encouraged to attend on a "needs only" basis; many growing tendency to consider everyone with HIV infection as a patient at all times and they became dependent upon drugs, even when they had no active opportunistic infection. Through health education

[70] Hampton, J. (1991), p.11
[71] See also Chaava,T. (1990)
[72] in: "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions.", by Sr.Kay, MMM, Kitovu Hospital, Masaka (1994), p.2.
[73] Group Counselling includes talking about sexual behaviour and prevention, physical symptoms and effects of treatment, advise in diet.

at the clinic and paying attention to the effects of anxiety on the person, attendance for drugs has been reduced. How ever, it is still a problem that once they come to the clinic, they think they must get drugs."[74]
1993, 158 patients were registrated by the Home Care and 550 visits were done.[75] The high rate of AIDS patients in the Rakai District and limited resources in giving support are reasons for changing the options of Home Care Service. The consequences of limited resources were shown by the high rate of died patients: "Since patients are only placed on home care when they are too weak to come to the hospital, there is a high death rate; of the 158 patients registrated in 1993, 47 had already died by the end of the year."[76]

Support on Community Level
"It is important to note that at the beginning of the project, it was common practice for people to run away from our counsellors and no to be seen entering our project offices. Clientele who had courage to be registered cautioned counsellors not to visit them in their villages with the project's red motor cycle that was well known to the community. This definitely slowed down the rate of behaviour change and did not provide conductive atmosphere for community based AIDS care and support."[77] The Aber Community AIDS Project sees this as the main problem to overcome prior to community support. But especially in areas of insecurity, like in the northern districts of Uganda, support structures on community level are extremly important if not vital.
Information, education and training with different methods are ways to get in contact with fears of society. "At community level, the improvement in AIDS awareness through community mobilisation, AIDS education at various forums, training community AIDS educators that are still on-going have gone a long way in demystifying HIV/AIDS. This has created a supportive atmosphere that encourages people infected and affected with AIDS to seek AIDS care, support and information. Family members and communities are now taking an upper hand in educating and caring for their sick."[78]

Finally, the Palliative Medical Care, especially adequate pain relief, has to become a part of the home care support at the community level.

5.2 The Hospice Concept and Approach

You matter because you are you.
You matter to the last moment of your life,
and we will do all we can
to help you not only to die peacefully,
but also to live until you die.

Cicely Saunders

A Hospice is defined as a place of relief of emotional and physical suffering of terminal patients. Although the term is in Europe used from the time of Middle-Ages, a true holistic approach is of a more recent date. The first modern Hospice was founded in London in 1967 by an English nurse, social worker and medical doctor Cicely Saunders. Nowadays, there are mobile and stationary Hospices all over the world: in Canada, Scandinavia, Japan, South Africa, America and Europe.[79]

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[74] in: "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions.", by Sr.Kay, MMM, Kitovu Hospital, Masaka (1994), p.23.
[75] in: "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions.", by Sr.Kay, MMM, Kitovu Hospital, Masaka (1994), p.23.
[76] in: "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions.", by Sr.Kay, MMM, Kitovu Hospital, Masaka (1994), p.23.
[77] in: Aber Community AIDS Project, Progress Report on the Activities of the Project from Inception to April 1994, p.4
[78] sic
[79] Examples of Hospices in Great Britain and Germany, as well as an example of holstic approach in counselling of AIDS Patients by the London Lighthouse, is given in Annex I.

In developing countries is the concept hardly known. Nevertheless, some countries are known as searching for a different approach and care of terminal patients. They are called Drop-In-Centres (Philippines), Day-Care-Centres(Uganda) and Rebirth Houses (Thailand).

Options
The term "Hospice" means above all a *concept* not an institution, giving ample opportunities to different models according to specific needs and local conditions.

Mobile or Ambulatory Hospice
Medical Care, Nursing and Counselling of the patient and his relatives at home.

Day-Clinic:
Patient is stays only during the day at the centre to give family and relatives a chance to rest, to recover and to find a new energy to cope with the situation. For medical or social reasons there is a limited number of beds for a short admission period.

The Stationary Hospice:
The Stationary Hospice gives a full but specialised service comparable to a hospital but with counselling of terminal patients and their family or relatives during the leave-taking-process.

The main aim of a Hospice is: "**Living up to the end**."

The terminal patient should be in position to active participate in everyday live despite his/her physical condition and process of mourning.
The Hospice concept is based on the idea of providing practical help by medical and nursing care, as well as social support and counselling. The key component is not only a support of a patient in the moment of dying; it means above all counselling and support in all stages of an incurable disease to continue to live a meaningful life until the end.

The Hospice approach denounces medical measures aimed at life-prolongation, but rejects categorically the practise of active euthanasia.
Palliative pain relief measures are an essential part of the care because the physical pain would make acceptance of the given situation very difficult.. It is also of utmost importance to give the patient a chance to remain in close contact with the surroundings, to live the everyday-life as normal as possible (at home, with the family and friends).

In general, a patient with appropriate palliative treatment, in combination with a good nursing and counselling, does not become suicidal.

The counselling of terminal patients means to be guided by their own needs. A Hospice-volunteer, a nurse, a doctor or a counsellor play merely a supportive role. The patient has to go through all stages of disease his/her way and pace, followed and supported by the professional staff. It is one of the most important phases of the patient's life, providing the staff with an opportunity to share that experience, being both exhausting and enriching.

5.2.1 Life and Death in the Cultural Context.

A human, dignified dying, is often seen in a respect of the past life and a prospect of a natural next step: the death. Reaching that stage, terminally ill patients should not disappear in a loneliness and anonymity. The should be supported in the moment of this final period, like the midwifes take care of the first steps of a new life.

In Europe, 90 % of citizens die nowadays in hospitals or in houses for aged people. In general, the process of dying is isolated from its social surroundings, from the family, relatives and friends. These are the results of loss of the traditional behaviour of initiation and leave-taking. It is a reflection of our fears concerning changes in life and our longing for (professional) care. Moreover, it is caused by a evolution in the Western society, where economic interests prevail over the cultural ones. There is a shift of values from those connected with emotions towards more rational ones. On the long run, the personal exchange of experiences can be at stake, as an experience with own emotions is getting less or even lost, leading to an increased fear of confrontation with emotions of others.

Every society is confronted by birth and death of her own members. These most important periods of life are marked by strong emotional and physical experiences and not easy to cope with.

Number of coping mechanisms exists to avoid a direct confrontation with a life threatening situation: emotions can be suppressed (especially concerning of own death) or devolved through a group action (religious and traditional ceremonies, cultural rites, etc.).

Another possibility is become increasingly detached from own emotions. Especially the "modern" and industrial societies have based their approach of everyday life in rather materialistic way. The milestones like birth and adulthood are still alive in Christians ceremonies and celebrations (baptism, marriage etc.) but the emotional link is getting lost. Celebrations are still popular as a kind of cultural, social integrated and accepted event. But initiations like these are milestones of life and, reminders of its finality.

5.2.2 Hospices in sub-saharan Africa

In sub-saharan Africa some Hospices are already established[80], other countries[81] envisaged to establish Hospices. 1980 the first Hospice in sub-saharan Africa was established in Zimbabwe, based in Harare. Hospice Zimbabwe started their service with a Home Care team. The Day Care Centre was opened in 1992. The home care service is geared more to the needs of the white Zimbabwean. This explains the present developmental stage of this hospice. The service uses a number of beds in a Hospital for palliative care, especially reserved for AIDS patients.[82].

The Nairobi Hospice, Kenya, was started taking patients in late 1990. "Using the modern concepts of pain and symptom control researched in other Hospices and introduced for the first time to Kenya by Nairobi Hospice, we are managing the majority of Nairobi patients at home with their families. (...) The aim of our work is that all patients dying of cancer or other terminal diseases such as AIDS my have this care available to them throughout Kenya.".[83]

In 1993, Hospice Uganda was founded, and is now established in Mulago, Kampala.
Hospice Uganda consist of a home care program, training for local staff, and training for health professionals in Kampala and the provinces. As a model of *Hospice Africa*, Hospice Uganda train also health professionals from other African countries and give them chance to get field experiences working together with the Hospice Uganda team. "Hospice Africa is a new charitable organisation which aims to be a catalyst in bringing palliative care to cancer patients and their families in countries in sub-Saharan Africa.(...) Hospice Africa hopes to carry out the following:

- Set up a model hospice in Kampala, Uganda, in association with the Makerere Medical School. (...)
- The Hospice Africa Training Programme in Kampala, to enable us to invite those wishing to set up a hospice in their own country to come to us for periods of six weeks to three months, working beside us, while receiving formal teaching in administration, the initiating of a service with the hospice spirit, and the relevant skills in palliative care. These initiations will then return to their own country, supported by us with advice and possibly an exchange of staff to allow them to set up

[80]Zimbabwe, Swaziland, Kenya, Uganda.

[81]Nigeria, Tanzania,Cameroun.

[82]Merriman, A. (1993)2

[83]in: Nairobi Hospice, First Annual Report 1989-90, Nairobi, p. 19

an appropriate service.
- Liaison with already established hospices in sub-Saharan Africa, sharing training and experiences."[84]

Discussion

Hospice as an idea and concept of a comrehensive care seems to be practicable in the Western as well in other cultures. Realisation of the Hospice concept in in other cultures has to undergo an aculturation process.
Kind of the Hospice and its manner of support has to be addapted to individual needs of the patients and their relatives. Their cultural, social and economic background will influence the needs as well as the methods, manpower and financial resources.
In high HIV prevalence areas with low economic resources, the Hospice has to cope with a disproportion between the number of patients in need and available funds. Limited resources ask for appropriate choice of a type of hospice.
The choice will depend on answers to the questions like:
- which kind support is needed (ambulatory, day-care or stationary) and feasible (availibility of the manpower and finacial resources, participation of the patients and their relatives)?

It seems that in the given cultural and economic situation of many African countries, stationary Hospice is not a feasible option. Is serves a limited number of patients and is very expensive while a overwhelming majority of the patients continue to suffer unattended.
A more feasible alternative is a day-care centre, together with ambulatory Hospice. They can assist most of the patients and their relatives, provided basic requirements can be met such as material support and comprehensive health care, the latter ncluding appropriate palliative medical care.
Nevertheless, this requires additional investments in training of medical professionals in palliative medical care, an increase in import and use of opiates (morphine) and more research into:
traditional and modern ways of coping mechanisms in the terminal stage,
traditional ways in coping with pain and
alternatives to existing pain relieving drugs.

[84]Merriman, A. (1993), p.23

6. Training and Supervision of the Staff involved in Counselling

Training and supervision of the staff involved in counselling as already described in 4.3, needs a special attention. Effects of overworked or "burn out"-symptoms should be prevented by a professional training, which do justice to the physical and psychical condition of work, as well as regularly supervision of the staff.

Multisectoral-Training
Due to the challenge in areas high prevalence by HIV/AIDS, a more comprehensive training staff in medical, nursing and counselling issues should be ideal. Especially Home Care teams will become more effective, if e.g. a counsellor is also trained to do examinations and to prescribe drugs. A mobile unit with interdiciplinarly trained staff can do more effective work, than a separate working team[85] and patients will have to tell their social, psychical and physical problems only one time and to one person.

Training of Counsellors
Counsellors need not be formal health care providers: teachers[86], social workers, CHWs and TBAs etc. are also suitable, but education, training and supervision will be needed. "Although we have trained counsellors we are beginning to realise that AIDS counselling in our setting is not wholly the business of a professional counsellor."[87] Para-professionals will be trained to provide counselling support. "The training is designed to teach para-professionals active listening skills to cope with the spiritual and emotional dimension of the person who is HIV-positive."[88]

Participants
It will be important to have a staff of different ages and social-economic backgrounds. A variety of different experiences of life give also a variety of methods of counselling and the possibility to address the patient in familiar way. Addresses of training courses for counselling often are working in the field of Counselling, Pastoral Care, Social Work, Medical support, as Health Workers or Teachers[89]

HIV-infected counsellors
It would be a tremendous help to integrate HIV-infected counsellors in the team. "We would like to build on our experience with one person with HIV who has become an effective counsellor and have more persons with HIV on the counselling team."[90] Counsellors with own experiences in being HIV-positive are closer to the needs and emotional situation of clients. To follow a policy of actively recruiting people who are HIV-positive as counsellors means also to accept that they are falling ill more often than healthy people.

Traditional counsellors
It will be also helpful to ask for integrate the experiences of traditional counsellors and invite them to participate on training programs. "Available literature shows that old people were seen as sages who could not only offer suggestions but were expected to give advice and at times provide answers to questions. African counsellors, unlike their Western counterparts, were expected to give a "word of wisdom". The non-directed counselling advocated by Westerners had no place in the traditional African approach to counselling. What this means is that for the Western type of counselling to be effective in our cultural setting, some modifications are needed."[91]

[85] There is a problem of coordination of mobile units in due to the different needs of time in nursing and counselling.
[86] There is also a lack of educating and training teachers in being confrontated with the emotional situation and needs of orphans.
[87] Kalibala,S.; Kaleeba,N. (1989), p.174
[88] Ego, M.L.; Moran M. (1993), p.85
[89] It will be also necessary to discuss other ways of teaching and give advice in methodic and didactic, as well information about human development.
[90] Ego,M.L.; Moran,M. (1993), p.91
[91] Munyoki,S. (1991), p.75

Health Workers
"For health workers to acquire the skills needed for HIV/AIDS counselling, training programmes will be required. All health care programmes dealing with HIV-infected people should include counselling and appropriate counselling training for staff." [92]

Ex-patriate Volunteers
"In Africa, there is a good sources for volunteers in the expatriat wives who are usually not employed. However the drawback is their lack of knowledge of the local language and culture. They can however give great support in the management and administrative areas, maintenance of equipment and materials for loaning to patients, raising funds, transporting patients etc."[93]

Aims of the Training
"The training is designed to teach paraprofessionals active listening skills to cope with the spiritual and emotional dimension of the person who is HIV-positive." The training includes a discussion of "feeling words as they are spoken in the local languages used by the group."[94] "There is a profound learning in how to walk with someone through the dying process to their death and how to continue to be a healing presence to the family after the death of their relative."[95]

Counsellor Training Courses should included factors, like ...
- training in differences in counselling of people different ages
  (e.g. different emotional needs of clients different ages)
- special issues of human development, social and sexual behaviour
  (like sexual activity of young girls: raped girls, prostitution of orphans, etc.)
- training in differences in counselling of people affected by HIV/AIDS in different ways
  (patient, spouse, parents, children, brother and sister, friend)
- training of terminally ill patients in the last stage, and their relatives
- traditional and modern coping mechanism
  after experiences of sick and dying relatives
- experiences with alternative methods and
  training how to use these methods in counselling
- experiences in recognising signs in non-verbal communication
- recognising own energy resources

The Cultural Aspect in Training of Counsellors
A extremely high financial engagement by nearly 10.000$ for a 6-month training course in England[96] might be one of the arguments to integrate training courses for counsellor in the national training program. It will be much more effective to invite lectures and counsellor trainers from other African countries with field and methodical experiences, than to send only some counsellors to a training in western countries where western cultural issues and methods will be discussed.

Monitoring and Supervision
"It is becoming obvious (...) that, as the numbers of clients increases, the staff themselves need more emotional support. Efforts to address these issues so far have included debriefing counselling sessions with the supervisors and monthly HIV/AIDS Committee meetings where the counsellors concerns can be raised. As the level of need for staff support increases, we wonder how we can meet the need and maintain the quality of the counselling."[97]

Supervision of long term support givers should included following issues:
- coping with personal less supported situation
- coping with personal affection by HIV/AIDS
- coping with emotional effects of giving support of terminally ill and dying patients and their relatives

[92] WHO (1990), p.9
[93] sic, p.8.
[94] Ego, M.L.; Moran M. (1993), p.85
[95] Ego, M.L.; Moran M. (1993), p.90
[96] included tiket, food and accomodation.
[97] Ego, M.L.; Moran M. (1993), p.90

- managing own resources of energy
  (acceptation of limited working time and no personal financial support[98])

Recovering program for the staff will be necessary, due to prevent "burn-out"-syndrome.
- searching for possibilities to share together the lunch time
- find a quite staff resting room for relaxing during the several meetings with patients
  and for emotional moments, when a private area will be needed (e.g. mourning phase)
- regularly excursion with the team, e.g. picnic

The Role of Head and Administration of NGO in Monitoring

Need of responsibility for the physical and psychical working-condition of the staff by the head of the support organisation. "Those in administration have had to be aware of the emotional strain on staff in caring for many young people who are dying, and not having the joy of seeing most patients healed. Staff need skills in how to cope with stress. At the hospital seminary on how to deal with stress were made available to all members of staff." (Nsambya-Hospital, Kampala)[99]

Sensitive people with strong social engagement are looking for a job in social enviroment. E.g. a counsellor, who visit six days per week people affected by HIV/AIDS, who is open to hear their social, physical and psychical problems to cope with their situation, need time to recover and to cope with his own emotional and family situation after work. If patients are coming late in the night or on Sunday to those counsellors which are well known by their friendly support, the counsellor is not trained to take his own time for recovering. If sources of material assistance are empty, but a patient ask for help, because he and his family had no food since 4 days, the counsellor, who is involved is sometimes prepared even to give this family part of his own salary.
The reaction of those counsellors are understandable, because it is a human need and answer of those, who ask for help. But a counsellor, often also affected by family members suffering by HIV/AIDS, without material assistance and financing support, with own children and without enough salary to pay school fees, often not enough, to take care of his own family, when he fall sick, this counsellor need regularly psychical support and counselling to cope with his working conditions. Regularly supervision by extern supervisor will be helpful, as well as the psychical support by the head and administration of NGO and suitable working conditions.

[98] In case of being informed about the private address of supportgivers, patients and their relatives often ask for financial help directly. Patients often also not accept the need of supportgivers to have relaxing time, especially by night. It will be important to give the supportgivers emotional support and technical methods, how to answer these asking for help and protect their own recovering time.

[99] in: AIDS integrated activities at St.Francis Hospital Nsambya and Home Care Service, Annual Report 1993, p.2.

7. *Generation's Concept*

AIDS is more a social problem
than only a health problem.[100]

Counselling of People affected by HIV and AIDS included all these ones, who participate at the discrimination and suffering in case of HIV and AIDS: The HIV-infected person or AIDS patient himself, as well as his family, clan and his friends. In social meaning, counselling of People affected by HIV and AIDS included also the different generation of the society: the elder, the productive adults, the Adolescents, children and the youngest. Due to a weak society, affected by HIV/AIDS and other diseases (TB, Cancer) which reach and reduce the productive generation, the social structures in the younger generations will be more and more loosed and unknown.
In case of an expected problem of less social behaviour in the next generation, which grown up with experiences of non-family-structures[101], dying parents and less- or non-supported life as an orphan, the options for Counselling of People affected by HIV/AIDS has to be more difference in the needs of each generation.

The author therefore suggests to use a term *Generation's Concept* to distinguish different needs of the different age-groups. This provides also an opportunity to define the aims and the methods to reach them in a more appropriate way. The concept combines field experiences of the social worker, health worker, medical personnel and the teachers, as well as of the counsellors who are working with people affected by HIV/AIDS.

The *Generation's Concept* distinguishs the following generations
- the Young Generation (the Youngest, the Children and the Adolescent),
- the Generation of the Adult and
- the Generation of the Elder.

and is based on 6 different topics, which describes the needs in managing the everyday-life, coping with several leave-takings being affected by HIV and AIDS, as well as preparation in build-up a new, self-confident generation for the future.

1. Basic Care
   means the basic needs in everyday-life, like food, clothes and hygiene
2. Psycho-Social Support
   means counselling in different ways to search for well-done coping mechanism,
   as well as for getting a feeling of companionship in different stages of life
3. Basic Health Education
   means the advise in the basic hygiene and prevention
4. Social Life
   means the chance for meeting other people with same experiences in a special stage of life,
   as well as to meet people with other experiences.
5. Education & Training
   means an offer of being educate or advise in different skills for the chance to get a profession, living an active life or/and to support charity projects.
6. Job & Trade
   means to get a chance of realising the personal skills, to sell the self-made products and to build up a basis for trading.

[100] Counsellor of the Diocesan AIDS Commission in Jinja, Uganda.
[101] see Glossary *Family*

7.1 The Cultural Aspect in the *Generation's Concept*

It will be necessary to give support in the traditional and cultural way, as well in adapted modern ways.
A culture and its social customs do not only consist of traditions of past social communities; on the contrary, each community must discover social behavioural customs which adequately correspond to the times. Traditional social customs and rituals appear to form a good basis for managing new tasks in social co-operation and personal psychological demands.

The advising in traditional skills and coping mechanism via the reintegration of elders, will be one of the helpful methods to teach the younger generation in their own cultural behaviour and to promote a dialogue between the modern and the traditional way of living, as well the reborn of cultural self-confidence in the modern society.
"Available literature shows that old people were seen as ages who could not only offer suggestions but were expected to give advice and at times provide answers to questions. African counsellors, unlike their Western counterparts, were expected to give a "word of wisdom". The non-directed counselling advocated by Westerners had no place in the traditional African approach to counselling. What this means is that for the Western type of counselling to be effective in our cultural setting, some modifications are needed."[102]
In this field, the Counsellors have a tremendous chance to promote the way. Organisations which are involved with care and counselling have, through their work, not only the opportunity to directly observe the development of social behavioural customs, but also to shape influence them and to encourage others to join into this process.[103]

In the care and counselling of patients, the personal needs of the patient should always be taken into account and his/her social surrounding should also be considered fairly social and cultural behaviour should be considered as much as the limitations of the given economic situation. For these reasons, the adaptation of an western concept for the caring and counselling of HIV/AIDS patients in another culture, such as that in Uganda, without considering the difference in culture, would be unfeasible.[104]

For the development of methods in counselling, it will be needed to do research about cultural and traditional methods. Talking, as one of the primary methods in western counselling, is not in every case and every culture feasible. Talking about private and intim issues might be a hurdle in expressing own emotions in front of another person. [105]
There are cultural differences in expressing emotions, which are based in the variety of methods of communication. Each Society has different priorities in representing their messages. In western cultures, where people are mainly fixed of visual methods (promotion, TV) and the verbal communication (talk, telephone), in counselling a method-combination of painting and talk will be optimal.
Like in Africa, where visual communication is very low, other alternative methods, like music, dancing and accepting of dreams[106], have to be more recognised and counsellors have to be trained.
"It should be pointed out that we are not saying that the Western concept of counselling is of no use to the African. What we are saying here is that counselling as a process needs to be contextualized in its approach so that it can meet the needs of the African people in an African setting."[107]

Nevertheless the Concept can be applicable to the African situation, too, provided the sufficient man power and its appropriate training are available.

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[102] Munyoki,S. (1991), p.75

[103] An example of changing behaviour by counselling will be given in Annex III.

[104] "If counselling is to be effective it must be seen by the client as acceptable." (WHO (1990), p.12)
: social relationship, commitments, obligations of the individual, fully acceptance of the HIV/AIDS patient's life-style, sexual preference, socioenconomics, ethnics or religious background.

[105] see Glossary *Talking*.

[106] "In Africa, dreams are of tremendous importance (...) Many people believe that during a dream the soul visits the spirit world, ..." (Knappert, J. (1990), p.76)

[107] Munyoki,S. (1991), p.74

7.2 Counselling of different Age-groups

Different age-groups, patients and threi families alike, have different counselling needs. Especially in the situation of being affected by HIV/AIDS, different level of involvement demands various ways of approach. An older person can live on the past esperiences, while an young adult usually feels cheated and furious, not prepared to die "so early". An infected father may look for the support of his family after his death, while grandparents are looking for the future-care of orphans. A 15-years old will be annoyed by the early death of his younger brother, dying by AIDS, and feel himself overburden for taking care of the other sisters and brothers. Counselling of people affected by HIV/AIDS means to be open for the individual situation, without missing an overview of alternatives of giving support the next generation.

5 Criterion of Differences in Counselling

1. Age
2. Social Background
   - single, married, window(er), child, orphan[108]
   - social surrounding, livelihood[109]
3. Physical Condition
   - healthy, HIV-infected, AIDS patient, other health problems[110]
4. Relation to the infected/sick Person
   - partner, child, spouse, parent, family member, friend, neighbour, colleague
5. Experiential Background
   - experiences in relationship (trust, mistrust, love)
   - experiences with issues of leave-taking (bereavement)
   - recognising own emotional and spiritual sources[111]

The *Generation's Concept* gives examples of different methods in counselling of people different ages. These methods are based on the human development, social experiences and needs of the people different ages, as well as the methods will oriented by the important aims of the concept:

Important Aims of the *Generation's Concept* are ...

1. Generation of the Youngest:
   Basic Care and building relationship (regularly contact person).
2. Generation of the Children:
   Basic Care, building relationship and experiences in social structures.
3. Generation of the Adolescent:
   Experiences in social structures, prevention and social behaviour, education and job.
4. Generation of the Adults:
   Care, counselling and (palliative) medical care for those who are already infected or ill, prevention and social behaviour, companionship in self-help- and support-groups.
5. Generation of the Elder:
   Care, counselling and reintegration in the social life.

Methods of counselling should anticipate on individual and social needs of the client. The centre support and the relation support will complement each other in the social support of the *Generation's Concept*.

The Centre Support (strenghtening of own ego)
- becoming self-centred
- searching for the individual meaning of life
- getting experiences of enjoying different parts of human life (body, soul, mind)

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[108] See Glossary *Cildren, Marriage, Family, Orphans*.
[109] See Glossary *Rual Life, Urban Life*.
[110] See Glossary *Health*.
[111] See Glossary *Spiritual Life (iii)*.

The Relation Support (strenghtening of the relation with the direct social environement)
- recognising relations of trust (relatives, friends)
- take part of self help groups
- getting contact with other HIV/AIDS patients
- build up new relations with infected and non-infected people

The Importance of Counselling the Young Generation

"We have to protect this young generation more than the adult. Unless we do that, than our country would finish.", states Ugandan counsellor Robina Kasadha as a conclusion of her work on care of orphans in Rakai area, south-west of Uganda and most affected area by HIV and AIDS.[112]

The report of The Economist Intelligence Unit 1993/1994 (p.13) demonstrate the relation between prevention and HIV-infection of the Adolescent in Uganda. "The survey focused on those aged 13 or more and revealed that 3% of those respondents who were seronegative in 1989 had become seropositive one year later, with the highest rate (about 10%) in the 20-24 age group. It also showed that the most important risk factor was the number of sexual partners, with some subjects reporting three ore more during the survey period. The authors of the report suggest that their figures represent an underestimate of the true situation because many of those they failed to follow up belonged to the high-risk groups. The public health implications of this report are very discouraging for the authorities. Knowledge about AIDS in the survey group was almost universal and most of them had some AIDS education, and yet the proportion of people admitting to having multiple sexual partners had increased significantly from 8.9% to 12.3% in only one year. The figures reflect the difficulty of implementing effective measures to contain the epidemic in Uganda and underline the need for better strategies."

The following diagram will demonstrate the given situation of already infected Adolescents in Uganda.[113]

HIV infected Adolescent in Uganda (June 1991)[114]

Fout! Onbekend argument bij schakeloptie.

It will be necessary to build up a special Counselling programme for the Young Generation which gives special support for each case: Being affected as a family member, orphan, being infected by HIV or already ill by AIDS. Counselling the Young means also a challenge of behavioural change for the counsellor. "In dealing with the youth the counsellor needs to remember that these are children and, therefore, are likely to be different from adults."[115]

Major factors in differences between Counselling of Adult and Youth: [116]
- the youth are likely to be lacking knowledge and maturity, therefore, less capable than adults of dealing with matters relating to sex and death
- the youth are likely feel uncomfortable discussion such issues as sex with adult counselling
- the youth may show rebelliousness towards adults and society in general as is normally the case of individuals going through the adolescent crisis
- the youth may be more bitter and resentful than adults because many young people have difficulty controlling their emotions due to lack of maturity
- the youth may be experiencing feelings of rejection at home and, therefore, difficult for him to trust the counsellor because he or she is viewed as an authority figure and not different from rejecting parents at home
- the young may feel that he has more to lose than an adult victim of the disease since he has lived only small portion of his life

[112] in "These are our Children", Video Movie by Jamie Hartzell

[113] Reasons for infections might be: "Unfortunately, some of the infected adolescents, especially the girls, have become infected in situations where they had no control over the sexual activity. Such situations include forced marriages, incest, rape and cases where poverty or other conditions force girls and young women to sell sex for survival. In some cases, poor parents force their daughters into prostitution. A girl might be asked by the mother to go inti town and use her resources to get food for the family." ("The bitter daddies ... and the outrage against young girls" (in: The Standard, Kenya, 01.05.94, p.5)

[114] "The bitter daddies ... and the outrage against young girls", in: The Standard, Kenya, 01.05.94, p.5

[115] Ego,M.L.; Moran,M. (1993), p.78

[116] Ego,M.L.; Moran,M. (1993), p.78

7.3 Differentiaton of the *Generation´s Concepts*

7.3.1 Generation of the Youth

The Youth of Uganda is affected by HIV/AIDS in different ways. Often they are affected by a dying member of family or clan. Many children and adolescents already lost one or both parents.
A great number of the youth also is affected by an infection by HIV, because of blood transmission by an infected blood-donor[117] or by prenatal transmission.
Low education[118] and sexual behaviour of adolescents often are reasons for higher risk of infection by HIV in this age group. "Young people may influence one another to continue to indulge freely in sex on the grounds that other generations have always had "good times". It was thought that the "in-betweens", that is, those old enough to marry but not yet married, are least likely to change behaviour. They are the most vulnerable and at risk group."[119] The AIDS Commission of Diocese of Jinja reported about a presently sero-prevalence rate HIV positive of over 20% of young adults in the area Jinja, Iganga and Kamuli.

Orphans
In Uganda approximate 20.000 children become orphans each year, 1.8 million orphans already exist.[120]
Aber Community AIDS Project assists more than 500 orphans with food only. Their number, as reported, increase daily. Orphan's Program of Kitovu-Hospital shortly expect 10.000 children in very young age-group, who need continual social and material support (basic care, material assistance, school-fees and -material). These supported children will be only 5% of all orphans in need of Rakai-Masaka-District.

Orphan's living Situation and social-economical Reasons of their Behaviour
- Orphans have long-term emotional experiences in take care for weak, suffering and dying parents.
- Oldest child (often not older than 12 or 14 years) has to look after a number of sisters and brothers, after death of both parents. They are challenged to take over the role of mother or father alreadz during their childhood.
- Orphans are affected by grief, hunger and poverty.
- Often orphans loose their right to live further in the family's house, because relatives overtake the rights or the rent can not be paid.
- Often in case of adoption, sisters and brothers also loose each other, because of distribution to different families.
- Adopted children often are discriminated by the family ("children 2nd class")
- When e.g. mother left with a big number of children, the older children often are going their own ways and become Street-Children, caused not being a burden for the weak economical situation of the family.
- In the same situation, girls also will be send by their left parent to earn money by prostitution.
- Prostitution is often especially for young girls the only alternative to earn money for buying drugs for the suffering parents or to support their sisters and brothers after the death of the parents.

Sexual Activity of Girls
"It seems that older men are infecting young girls in this 15-19 age group because if boys in the same age group were infecting the girls, the infection would show equally in both groups. As we see, that isn't the case."[121]
A study of orphan's behaviour in Masaka Diocese (South Uganda) shows a raised rate of sexual activity of girls by the age of 12 (30%) up to the age of 18 (85%).[122] Reasons for this behaviour are limited support of orphans

[117] Especially little children with an anaemia caused by malaria are treat by blood kits. Since some years normally there are possibilities to do blood screening of HIV and Hepatitis.
[118] The need of free primary education are already in discussion by ugandan goverment, but financing is still not clear.
[119] A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.26.
[120] See also A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.21.
[121] Sharpe/Kaleeba (1993), p. 7.
[122] Flint, J. (1994), p.108.

(poverty), the possibility to earn some gifts[123], and a special predilection by men for young girls who are supposed to be free of infection.

Fout! Onbekend argument bij schakeloptie.%

Basic Care

and experiences in social behaviour, as well as to build up relationship can be best offered in social structures of a family. Adopted orphans should be supported by an orphan-fund, who take care for food, clothes and school-fees. With in there will be no conflict among the supported orphans and the unsupported children of the family, in case of low budge it should be possible to give support for all children. To be integrated in a family, living in the home area and the same ethnic group, will be the best care of orphans.

Projects, like SOS-Kinderdorf and the family-project by the Kamwokya-Parish[124], tries to build up new families (mother and 6-10 children), as alternatives for orphans, but cannot cope with ever increasing demands.[125]

Orphanages

are often no alternatives do justice to the needs of children, because social contact are missed. The children get used to be supported by material assistant without a real relation to social situation. Reintegration in community often become difficult, because the children are used to get food by institution. Orphanages are also no long-term answer in case of generally weak economical and low financial situation.

[123]E.g. school fees and clothes.

[124]Kamwokya is a district in the North of Kampala with a high rate of people affected by HIV/AIDS.

[125]Most of the women have already 6 or more children of themone.

School Fees
for a children in Rakai-Area amount approximately 60 $ per year.
Schools especially looking for supported orphans, caused in low and unregularly paid teacher's salary, the teachers are welcomed regularly paid school-fees by orphan-funds.
Orphans often are missing school, because of none supported by a NGO or due to take care of the sisters and brothers. Low rate of orphans in school will be shown in a comparison of the rate visited orphans by the Pastoral Care and Counselling Service of Kitovu Hospital, Masaka, and those orphans, who are in school. "There is an overall increase in the workload of this section although more time is spent on return and follow-up care than on assessing new patients. Fewer social cases are being accepted from outside the hospital as an attempt is made to refer them to the Diocesan social programs if they are not patients."[126]

Fout! Onbekend argument bij schakeloptie.

[126] in: "Pastoral Care and Counselling Training Unit. Report of Evaluation Reflective Sessions.", by Sr.Kay, MMM, Kitovu Hospital, Masaka (1994), p.22.

7.3.1.1

GENERATION
OF THE YOUNGEST
(up to 4 years old)

Explanation:

*	special for the youngest with HIV and AIDS
vis-à-vis	vis-à-vis counselling with one person
group (f+m)	working with sex-separated groups of female and male

NEEDS		**METHODS**	**AIMS**
1. BASIC CARE	1.1 Food	cooking and feeding (by contact-person)	good nutrition*
	1.2 Basic Health Care	first education in hygiene	no infections
	1.3 Palliative Medical & Nursing Care	drugs*, painkillers* given by contact person	therapy of infections*, more comfortable living with AIDS*
2. PSYCHO-SOCIAL SUPPORT	2.1 Centre Support	playing and talking, experiences with own talents, body touch (vis-à-vis, group)	trust/mistrust-experiences, establish contact with own body, self-confidence
	2.2 Relation Support	playing and talking, games, music, (vis-à-vis, group)	regular relationship to a contact person, social acceptance, behaviour (group)
3. BASIC HEALTH EDUCATION	3.1 Hygiene	first advise in hygiene (group (f+m))	self-confidence by well feeling the own body, prevention of infections*
4. SOCIAL LIFE		"Kindergarten" (included traditional cultural tales, games and songs, individual (birthday)-party)	to learn social structures, getting cultural identification, acceptance of the individual, getting a part of the society
5. EDUCATION & TRAINING		trained in different skills (included traditional cultural skills and behaviour)	to motivate the individual talents, getting in contact with their own culture

7.3.1.2

GENERATION
OF THE CHILDREN
(5-11 years old)

Explanation:

*	special for children with HIV and AIDS
vis-à-vis	vis-à-vis counselling with one person
group (f+m)	working with sex-separated groups of female and male

NEEDS		**METHODS**	**AIMS**
1. BASIC CARE	1.1 Food	cooking (by contact-person, first lessons)	good nutrition*
	1.2 Basic Health Care	first education in hygiene	no infections
	1.3 Palliative Medical & Nursing Care	drugs*, painkillers* given by contact person	therapy of infections*, more comfortable living with AIDS*
2. PSYCHO-SOCIAL SUPPORT	2.1 Centre Support	playing and talking, experiences with own talents, sensitive feelings with the body (sport, massage), motivation to take over basic social responsibility (vis-à-vis, group (f+m))	self-confidence
	2.2 Relation Support	playing and talking, role play, dancing, music, little farming, cooking (vis-à-vis, group)	relationship, social acceptance, behaviour (group)
3. BASIC HEALTH EDUCATION	3.1 Hygiene	first advise in hygiene (group (f+m))	self-confidence by well feeling the own body, prevention of infections*
	3.2 Prevention	information about own body and sex differences (vis-à-vis, group (f+m))	telling about facts of life, self-confidence
4. SOCIAL LIFE		establishment a "Children Village" with the possibility of experiences of social self-management (included different modern and traditional cultural activities of social affairs)	to learn social structures, to take over social responsibility, getting cultural self-confidence and being sensitive for cultural differences
5. EDUCATION & TRAINING		school, trained in different skills (included traditional cultural skills and behaviour)	getting an education, getting in contact with their own culture (cultural self-confidence)

7.3.1.3

GENERATION
OF THE ADOLESCENT
(12-18 years)

Explanation:

*	special for Adolescents with HIV and AIDS
vis-à-vis	vis-à-vis counselling with one person
group (f+m)	working with sex-separated groups of female and male

NEEDS		**METHODS**	**AIMS**
1. BASIC CARE	1.1 Food	farming, cooking	good nutrition*
	1.2 Basic Health Care	trad.health care	no infections, treatment
	1.3 Palliative Medical & Nursing Care	drugs*, painkillers*	therapy of infections*, more comfortable living with AIDS*
2. PSYCHO-SOCIAL SUPPORT	2.1 Centre Support	talking, experiences with own talents, sensitive feelings with the body (sport, massage), motivation to take over more social responsibility (vis-à-vis, group (f+m))	self-confidence
	2.2 Relation Support	talking, role play, dancing, music, farming, cooking (vis-à-vis, group)	relationship, social acceptance, behaviour (partnership, sexual)
3. BASIC HEALTH EDUCATION	3.1 Hygiene	(group (f+m))	self-confidence by well feeling the own body, prevention of infections*
	3.2 Prevention	sexual information, information about HIV/STD- transmission (vis-à-vis, group (f+m))	prevention of HIV/STD-transmission, prevention of infections*
4. SOCIAL LIFE		"Youth Club" with different modern and traditional cultural activities of social affairs	to learn social structures, to take over social responsibility, getting cultural self-confidence and being sensitive for cultural differences
5. EDUCATION & TRAINING		school, trained in different skills (included traditional cultural skills and behaviour)	getting a profession, getting in contact with their own culture (cultural self-confidence)
6. JOB & TRADE		using the skills, trade, organising of bazaars and new sales-markets	self-confidence, bread winning

7.3.2 The Generation of the Adult

The generation of the adults is affected by HIV/AIDS mostly by illness themselves or/and being a partner of a wife/husband infected by HIV. "The other outstanding and grim feature of the graph is the level of infection in the 15-49 age group. This area of the graph, which peaks at the 29 age group, shows the reported number of people with AIDS at close 35,000. These numbers present a worrying picture because it is precisely this sector of society which contains young parents."[127]

Social-economic Effects

Due to the high prevalence by HIV in the most productive age group, effects in social-economical field are lack of man-power and problems in infrastructure of employment, as well a low GNP (Gross National Product). Caused by weakness, sickness or/and burdened by taking care for orphans, families affected by HIV/AIDS have tremendous problems to survive in economic terms. "A major problem is the loss of income due to the inability of people with AIDS (PWAs) to continue working once they fall sick. The PWAs often find it enormously difficult to provide for themselves and their families."[128]
"Parents fear that they will die, leaving their children with nothing. This appears to account, at least partially, for the present building boom in Uganda."[129] In Rakai Area for example, destroyed buildings by the war and unfinished buildings present the picture. Often parents die to early and orphans have no financial and physical power to finish the building.

Women's Situation

In some cases the wife, infected by her husband, will die earlier, cause by weakened immunsystem on account of frequent pregnancies, malnoutrition and heavy workload. But most women take care and nursing their sick and dying husband. When the husband dies and the woman fall also sick, women feeling themselves worse by being supported by their young children, and fears of the children's future are the most worse psychical problems in the terminal stage. "Single mothers who are sick with AIDS are also a significant social concern. Mothers are thought to deteriorate and die more quickly because of their fears for their children."[130]

In Nsambya Hospital, Kampala, 30% of tested pregnant women are sero-positive. "Staff had the impression that there were a significant number of women who had been coming to the clinic for 2 or 3 years but had not become pregnant during that time. They had attended before becoming pregnant in order to find out their sero-status. This in itself amounts to a change in behaviour. Many already had children but wished to be tested before risking another pregnancy. Most women prefer to be told their HIV status secretly. The husband may be told later."[131]

In areas with still existed discrimination and stigmatisation of people affected by HIV/AIDS, suicide as a reaction of a test-result being positive is not rare. Especially women, infected by their husband, often kill themselves after his death. These women have nursed his husband and seen him suffering and dying. In case of no children, many women are afraid of unsupported living-situation and loneliness in sickness and terminal stage. Women do suicide with malaria-drugs, like chloroquine, and often hang themselves, without getting in contact with person of trust.

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[127] Sharpe/Kaleeba (1993), p.6.
[128] in: AIDS integrated activities at St.Francis Hospital Nsambya and Home Care Service, Annual Report 1993, p.6
[129] A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.31.
[130] A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.30.
[131] A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.25.
See also Glossary *Women.*

GENERATION OF THE ADULT

Explanation:

*	special for adults with HIV and AIDS
vis-à-vis	vis-à-vis counselling with one person
group (f+m)	working with sex-separated groups of female and male

NEEDS		METHODS	AIMS
1. BASIC CARE	1.1 Food	cooking	good nutrition*
	1.2 Basic Health Care	talking, trad.health care	no infections, treatment
	1.3 Palliative Medical & Nursing Care	drugs*, painkillers*	therapy of infections*, more comfortable living with AIDS*
2. PSYCHO-SOCIAL SUPPORT	2.1 Centre Support	talking, experiences with own talents, sensitive feelings with the body (sport, massage), counselling in special issues* (vis-à-vis, group (f+m))	self-confidence, feeling more comfortable*
	2.2 Relation Support	talking, role play, dancing, music, farming, cooking (vis-à-vis, group)	relationship, social acceptance, behaviour (partnership, sexual)
3. BASIC HEALTH EDUCATION	3.1 Hygiene	(group (f+m))	self-confidence by well feeling the own body, prevention of infections*
	3.2 Prevention	sexual information, information about HIV/STD- transmission (vis-à-vis, group (f+m))	prevention of HIV/STD-transmission, prevention of infections*
4. SOCIAL LIFE		Self-help-groups (different issues, also morning-group), advising in different modern and traditional cultural coping mechanism	social integration, sharing problems, getting cultural self-confidence
5. EDUCATION & TRAINING		trained in different skills (included traditional cultural skills and behaviour)	feeling active and being needed, getting in contact with their own culture (cultural self-confidence)
6. JOB & TRADE		using the skills, organising of bazaars and new business contacts	self-confidence, bread winning

7.3.3 The Generation of the Elder

The generation of the elder are the generation of parents of those who are infected by HIV, and grandparents of the orphans. This generation has the experience of loosing members of the family by the war, but being affected by HIV/AIDS challenge the elder in a new way.
In their age normally the elder are being supported by their children. In case of loosing their own children dying by AIDS, the elder have to take care for their own life, often also supporting orphans. It is no exception, that a woman looses her husband in the war, her six sons by AIDS, and is left behind with a young daughter of school-age and her own old mother. In another case a grandmother is left behind with 12 grandchildren, in great need of care and emotional support, while the grandmother herself is in grief.

In case of loss of their family, older people often loose social contact and support in time of sickness. If there is no neighbourhood, old people stay without basic care and food.

There is a need to re integrate elder in the society, because social and traditional experiences of them are important for behavioural change and cultural tradition. Skilled workers of the generation of adults were left the country or already died. "People practised in some of the traditional rural skills are hard to find now. It was said, for instance, that drummers were very few."[132]

[132] A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.47.

GENERATION OF THE ELDER

Explanation:

*	special for elder with health problems
vis-à-vis	vis-à-vis counselling with one person
group (f+m)	working with sex-separated groups of female and male

NEEDS		**METHODS**	**AIMS**
1. BASIC CARE	1.1 Food	easy farming, cooking	good nutrition*
	1.2 Basic Health Care	talking, trade. health care	no infections, treatment
	1.3 Palliative Medical & Nursing Care	drugs*, painkillers*	therapy of infections*, more comfortable living with Cancer or AIDS*
2. PSYCHO-SOCIAL SUPPORT	2.1 Centre Support	talking, motivating of own talents, counselling in special issues* (included by burn-out-syndrome) (vis-à-vis, group (f+m))	self-confidence, feeling more comfortable*, getting information about aid
	2.2 Relation Support	talking, dancing, music, cooking (vis-à-vis, group)	(new) relationship, social acceptance, behaviour
3. BASIC HEALTH EDUCATION	3.1 Hygiene	(group (f+m))	self-confidence by well feeling the own body
	3.2 Prevention	information about HIV/STD- transmission (vis-à-vis, group (f+m))	prevention of HIV/STD-transmission
4. SOCIAL LIFE		"Club of the Experienced" (different issues, also mourning-group), recall of traditional cultural coping mechanism, tales, songs, etc. engagement in the "Kindergarten", "Children Village", "Youth Club" as a contact person or adviser in traditional skills	social integration, sharing problems, feeling to be needed and social acceptation, getting self-confidence to be an elder
5. EDUCATION & TRAINING		trained in different skills (included traditional cultural and modern skills and behaviour)	feeling active and being needed, not loosing own cultural self-confidence, but also being inte-grated in the new life style
6. JOB & TRADE		teach the younger generations in traditional skills, take care of the youngest	passing of personal and traditional experiences, self-confidence, bread winning

8. Conclusions and Recommendations

Conclusions

1. Social efforts
High rate of people infected by HIV and AIDS patients, as well as windows/windowers and orphans will continue to grow further straining the society and its resources.
In areas of social discrimination of people affected by HIV/AIDS, abandoned patients will need special consideration and attention.

2. Community Based Care
In high HIV prevalence areas, AIDS Care can be only provided as a Home Care and within Community Based Services, including proper Palliative Medical Care is included.
The Hospice-Idea as a concept and with ambulant services can be a viable alternative.
Due to limited resources, stationary Hospice in the given situation is neither appropriate nor feasible.

3. Material Assistance
Material assistance, including school fees and Income Generating Projects, will be necessary for those, which are too weak to look for their own basic needs.

4. Medical Care
Appropriate Medical Care is an important, but not yet integrated in Health Education and Prevention Programmes.
Palliative Medical Care ("pain relief"), as a part of treatment of terminally ill patients, is rarely practised due to limited number of well trained medical professionals and non availablity of appropriate drugs.

5. *Generation's Concept*
In a holistic approach, the social problem of living with HIV/AIDS has to take into account needs of the different age-groups.
A possible approach is in this study described as a *Generation´s Concept*.[133]

6. Support Organisations
There is a lack of co-ordination among support organisations, leading to a duplication and waste of scarce resources.
Despite of an excellent work, there is a danger, that the management and the staff of the support organisations do not recognise and/or accept their physical and psychical limits, leading to frustration and a high turn-over.

7. Rural Areas
Rural areas have only limited structures and resources for adequate social and medical support of people affected by HIV/AIDS.
In contrary to urban areas, there is relative stronger social discrimination of people affected by HIV/AIDS, seemingly caused by continuing lack of information and education about HIV/AIDS and behavioural change.

8. Role of the Catholic Church
On grassroots level, some excellent examples of AIDS Care by Church institutions and Church related organisations are found, while official Church policy is not very supportive.[134]
In addition, the communication between national and diocesan AIDS programmes is limited.

9. Role of Funding Agencies
In view of growing needs and dependency of people affected by HIV/AIDS, a self-sunstainibility will be hardly possible. It will be necessary to continue to assess current developments in
i) social structures and behavioural change,
ii) possibilities of comprehensive care of people affected by HIV/AIDS in developming countries.

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[133] See also chapter 7.

[134] See also "The AIDS Epidemic - Message of the Catholic Bishops of Uganda", in: "The Voice of the African Bishops" Serie 1989.

Recommendations

There is a number of challenges ahead to be dealt with. Some of them need immediate attention, others can be tackled later. They are formulated as recommendations and presented in the same ranking order as the conclusions.

Short-term Challenges	**Middle-term Challenges**	**Long-term Challenges**
1. Social efforts		
Continuos information to the public and care providers about the actual situation.	Discussion and developing of social concepts on national level.	
Strengthen the Education- and Preventionprogramms, especially in the topics - alternative ways of expressing love (sensitive touch, embracing, etc.) - the correct use of condoms (Information by pharmacist who sells condoms,visual information on each packing, information by published comic-strips, etc.)	Continuation of Education- and Preventionprogramms and work on special concepts for the different age-/sex-groups.	
Support (Home care, neigh-bourhood, Ambulant Hospice) especially for abandoned ones.		
2. Community based Care		
Expansion of support services as community based care coupled to income generating projects.		
3. Material Assistance		
Build up of funds for giving material assistance for those families in which the breadwinner is sick and weaken by AIDS.		
Build up of funds for giving school fees (directly to the bank) for children with sick parents and orphans.		
Expansion of Income Generating Projects		
Short-term Challenges	**Middle-term Challenges**	**Long-term Challenges**
4. Medical Care		

General permit for importation regularly a higher quantity of morphine[135] for palliative medical care, and relief in customs clearances.[136]		
Build up of funds for buying drugs for poor patients. Co-ordination of getting back non-used drugs if patient had not need it.		
Training in Palliative Medical Care.		
Start of discussion about the use of traditional and herbal drugs, co-operation with traditional healers.		
5. Generation's Concept		
To establish a group of inter-disciplinary experts (AIDS-counsellor, health-worker, social scientist, economist,etc.) for discussing in regularly meetings the possibilities of social development and creating of a Generation's concept for Uganda. To invite guest lectures from other departments to participate these meetings, will be refresh discussions and new ideas will be given..	To create a generation's concept, searching financial support for the first field experiences and projects. PR and discussion of the experiences in the public. Further discussions in interdisciplinary meetings. Work on the Generation's concept and make plans for the next phase.	Realising the planning of the first phase and discussing the experiences from the first phase. PR and discussion of the experiences in the public. Further discussions in interdisciplinary meetings.
6. Support Organisations		
Co-ordination of the Support Organisations and Home Care Services involved in support for HIV/AIDS patients and their families: To avoid waste of scarce resources.		
Supervision of internal structures in view of working conditions, which promote "burn out"-syndrome. Development of regularly intervals for recovering during the work (regularly meals, pauses, private weekend).		

[135]The more expensive MST is not necessary, if bying Morphine Sulphat powder is availabel. "If drugs are going down, the number of our patients is going down." :Dr. Miriam Duggan, Nsambya Hospital, Kampala about the need of getting regulary drugs as a part of trust in relation between support givers and clients.

[136]In co-operation with Cancer Support Groups, like Hospice Uganda. See also "The Cancer-AIDS-Relationship", see also 5.1 and 5.5.

Short-term Challenges	Middle-term Challenges	Long-term Challenges
7. Rural Areas		
Build up Home Care and Mobil Units, including Palliative Medical Care, in rural areas, and decentralise the AIDS-support from urban to rural areas.	Reintegration of people affected by HIV and AIDS in their home-/ rural area.	
Raising HIV/AIDS awareness in Communities by information, education and public meeting-points to get in contact with people affected by HIV/AIDS.	Use of alternative promotion methods (slogan on T-shirts, buttons,comic-strips) for spread the information about HIV/AIDS in areas without communication system, than oral-communication.	
8. Role of the Catholic Church		
Regularly visits of rural and urban areas, meetings with patients and diocesan AIDS-Co-ordinators for getting a realistic picture of the support situation and needs in areas affected by different social issues.	Active role in working on a Generation's Concept, together with the Diocesan AIDS-Co-ordinators and other NGOs.	
9. Role of Funding Agencies		
Funding of comprehensive community AIDS Care including: - basic needs (food, medical care) especially for children and person without income. - income generating projects - especially NGOs working in underserved areas.		
Funding of research into: - cultural practices - traditional counsellors - cultural coping mechanism for integration in modern education- and prevention-programmes - evaluation-methods for behavioural change	Refreshing and Reintegration of - cultural figures (taboo of premarital sexual intercourse, etc.) - traditional counsellors (aunt/girl, uncle/boy, elder) - cultural coping mechanism in the modern prevention- and education-Programmes	Awareness of alternative ways of expressing emotions: different ways of human contact, expressing by non-verbal methods (painting, etc.).

ANNEXES

Annex I

Short presentation of visited Hospices and AIDS Centres in Europe

1. St. Christopher's Hospice, Sydenham - London, Great Britain
2. Johannes Hospiz, Hospice in the urban area of Munich, Germany
3. Hospiz im Pfaffenwinkel, Hospice in a rural area of Bavaria, Germany
4. Mildmay Hospice, London, Great Britain
5. London Lighthouse, Great Britain

1. St.Christopher's Hospice, Sydenham - London, Great Britain

Founded in 1967 by Dame Cicely Saunders.

"The word "Hospice" implies a resting place for travellers, hence our adoption of St. Christopher, the Patron Saint of travellers. As a Christian and medical charity, we give skilled medical care to patients with advanced cancer, motor neurone disease and a limited number of patients with AIDS, as well as support to their families."[137]

Service
- in patient care
- Home Care
- day centre
- counselling for families
- training for professionals working with terminally ill patients and bereaved family
- National Hospice Information Service

"A distinguishing feature of "Hospice care" is that of "whole-person care" where the whole person is looked after by a skilled group of staff with input from the doctor, nurse, social worker, physiotherapist, occupational therapist, chaplain, volunteer (in short multudisciplinary care). We look after the patient's family as well as the patient, and our bereavement counselling service supports them in their loss."[138]

Nowadays the St.Christopher's Hospice seems to missed the contact to modern patient needs. The architecture of the late 60th with the 4-bed rooms is not yet adapted to the experiences of terminally ill patients who can not be confronted all the time with dying neighbours in face of their own dying. A needed silent room for resting and meditation is missed, as well as professional colour and lightning design of the rooms.
The training of the Hospice volunteers, which are directly or indirectly in contact with the patients and the mourning relatives, is limit on a 10-evening-lecture course. A short practical experience (3 hours on the ward) is included. Supervision does not exist.

2. Johannes Hospiz, Hospice in the urban Area of Munich, Germany

Founded 1992 by the Congregation of the Barmherzige Brüder.

Service
- home care
- stationary service (25 beds (1- and 2-bedrooms)
    - see also 1.
    - creative classes (painting, etc)
    - massage
    - 3 single rooms, bathroom, kitchen, restroom for relatives to be invite to stay over night

[137] St. Christopher's Hospice, Information Service
[138] sic

- restroom for the staff
- mourning-room (for taking leave of the dead relative in a private atmosphere)
- living room for the patients with a garden-entrance

Mainly Addresses are cancer patients, but also one or two beds are regular frequent by AIDS patients. There is a strong co-operation with the Schwabinger Hospital, which is the first address for Treatment of AIDS patients.

The Johannes Hospice is following the Hospice Idea. Three doctors, educated in palliative medical care, and special trained nurses are working on the ward. Regularly meetings and supervision for the staff and the volunteers are part of the team work.
The architecture and design of the restaurated old part of a general hospital, is adapted by the needs of terminally ill patients. The atmosphere is private and warm because their is a big acceptance for private wishes of the patients (interieur, pictures, animals, plants, own meals, etc).

3. Hospiz im Pfaffenwinkel, Hospice in a rural Area of Bavaria, Germany
Founded 1992 by a Society of donors, non-paid organist by doctors, nurses, social and pastoral workers in several towns in the area of Pfaffenwinkel.

Home Care Service
- in co-operation with private nursing-services
- Home Care and counselling by long-trained and regularly supervision volunteers
- palliative medical care in co-operation with private doctors and specialists
- Education and Information service
  for those who are interest to get in touch with the thematic of "leave-taking and death"

Mainly addresses are cancer patients (1993: 28 cancer patients, 2 AIDS patients).

4. Mildmay Hospice, London, Great Britain
"Unique as an independent Christian charitable hospital, Mildmay launched its AIDS programme by opening Europe's first AIDS Hospice unit in February 1988. The following year it became the national model for AIDS Hospice care."[139]

"By April 1992 Mildmay's residential care unit (arranged on three floors) contained 28 rooms and featured the innovative inclusion of family suites to allow children to accompany their ill parents."[140]

"A department of education, meanwhile, organises internationally recognised programmes and seminars for professionals in the AIDS care field. (...)New facilities are being planned, including an international study centre and specialist consultancy outpatient clinics in Uganda for people with AIDS."[141]

[139]MILDMAY HOSPICE, An introduction to ... London 1994
[140]sic
[141]sic

5. London Lighthouse, Great Britain

"A centre for people
facing the challenge of AIDS"[142]

HIV/AIDS care and counselling services in western countries are specialised in the medical, nursing and psychological care of HIV infected people, AIDS patients and their families.
The care offered by the London Lighthouse is a well-done example of such a complete and extensive service which includes medical, nursing and psychological care before and after testing. Publicity work and organising preventive measures form just as much of their work as out-patient and in-patient care of AIDS patients during the various stages.

Britain's first major residential and support centre for men and women affected by HIV and AIDS, placed in Western part of London, opened in November 1988. London Lighthouse has approximately 160 paid staff and 400 volunteers, and 1,600 people use the centre each week. ."The services and facilities that we provide here are to help you live a happier, healthier and more fulfilled life.(...) The main aims of London Lighthouse are to provide care and support, and to empower people affected by HIV and AIDS." [143]

In case of multiple discriminations (HIV infection, coloured skin, non-European culture, homosexual, etc.), London Lighthouse strive "to become an equal opportunities organisation. We oppose all forms of discrimination faced by people with HIV and AIDS, black people, gay men, women, lesbians, drug users and people with disabilities."[144]

Services which are provided:
- Drop-in centre[145]
- Café
- Counselling and support groups
- Creative and complementary therapies
- Day care[146]
- Community services[147]
- Education and training
- Residential services[148]

The special designed building.(well selected soft colours and materials) provide an optimal and well emotional support that people affected by AIDS can live their lives to the full.

There is a regularly training and supervision for the whole team (paid staff and volunteers), as well as workshops for people (professionals and para-professionals) who are involved in the issues of HIV and AIDS.
Annex II

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[142]Introduction to London Lighthouse, London, 1993

[143]At the Lighthouse, p.2, London 1994

[144]sic

[145]Services of the drop-in centre are Support and information service, Child care services, Qiet room, Legal advice, Women's sessions, Haircutting, Exhibitions, Exercise class, Tee parties, Knitting class, Garden, Safer sex (free condoms and information). (The drop-in centre, London Lighthouse, 1993)

[146]"The day care centre aims to provide a service for people living with HIV infection who need nursing care or psychological support, or both, during the day." (sic)
Service and complementary therapies of day care centre are one-to-one support sessions, individual and group therapy sessions (stress, anxiety management), creativ and social therapies, art class, anxiety management, health discussion, interest group, aromatherapy, relaxation/hypnotherapy, massage.

[147]The service includes emotional support, drivers, nightsitters, child care and practical help.

[148]Guideline for admission (residential unit) are convalescent care, respite care and palliative care. "The 23 bedded Residential Unit provides clinical care within a nursing-orientated, resident-centred environment. (...) The aim of the Unit is to create a safe, supportive and non-institutionalised environment whilst maintaining the highest standards. (...) The design of the Unit and its furnishing reflect this, and nursing staff do not wear uniform.(...) Services for residents incorporate an integrated approach to clinical care using conventional and complementary therapies. Occupational therapy, counselling and physiotherapy add to the overall package of care. Clinical decisions are made together with the resident's usual hospital or unit and firm lines of communication exist between London Lighthouse and the major treatment centres and units."(Residential Unit, London Lighthouse, London 1992)

Qualitative reasons which provide the starting points for a care and counselling programme and the consequences for counselling:

1. Fear of being infected by HIV

Receiving information and advice with regard to preventive measures, along with having a personal discussion and being accompanied at his/her first visit with an AIDS patient can be very helpful to a new

2. Fear of being stigmatised and socially outcast

Information organisations in the region itself, accompanied by preventive measures. Publicity work is an important component of the work of organisation and groups which support HIV/AIDS patients and their families. Their work should not take place behind closed doors of the social community.

3. Problem of confrontation with illness, dying and death

Discussion groups dealing with the themes of illness, dying and death. Discovery of old and new mourning rituals with the aid of role plays. Introduction of the special nature of life and death for the individual and the community (discussion, painting, music, dance). Enabling the individual to share in the experiences of the community.

4. Fear of taking on too much responsibility (maintenance for having to bring up additional orphans

Exhibit information and advice counselling on social support measures (foundations, donations), as well as organise self-help groups (child care etc.).

Annex III

Alternatives of Sexual Behaviour in a Ritual of Cleansing Widows/Widower.[149]

"There are some cultural issues which require specific counselling approaches. These issues include ritual cleansing of widows or widowers, the attitudes of women who are HIV+ and of childbearing age to further pregnancy, and sexual behaviour patterns in general. (...) The threat that this practice brings in the area of the AIDS epidemic is that many AIDS patients have spouses who are HIV+, and engaging in ritual cleansing by sexual intercourse can spread the infection to other family members." [150]

Ways of cleansing the widow/widower other than by sexual intercourse, three usual alternatives:[151]

1. Cleansing by passing a hoe under the widow/widower's bent knees. This takes place in the house where the bereaved individual sits undressed. The equipment is then given to the family of the widow/widower.

2. The bereaved person is made to jump over a cow which is lying on its side. The cow is later killed and the meat is used by the mourners.

3. A member of the deceased's family is made to sit on the widow/widower's lap. This is also done indoors and both persons are naked.

"These alternatives will not cause the spread of the virus. Alternative behaviour patterns can achieved as a result of counselling."[152]

[149]See also Glossary *Sex (ii)*.
[150]Chaava,T. (1990), p.85, ad. Cleansing ritual, look also Hoering/Wichterich (1991), p.161.
[151]Chaava,T. (1990), p.85
[152]Chaava,T. (1990), p.85f

Annex IV

Glossary "Terms of African Behaviour"

-> look also ....

Anomie

... as a result of social change
"In the urban centres, Kenya traditional values have disintegrated. We have abandoned our traditional ways, but have not quite mastered the urban culture. We appreciate it but we have not internalised it. Thus while we seem to adore the Western culture, we have failed to incorporate it into our personalities and, therefore, are left in astate of anomie (normlessness). While anomie as a product of social change is found everywhere in our society, it is more pronounced in the urban centres than is the case in rural communities. Anomie as a sociological term means a condition in which people are no longer governed by clear rules or norms as they were in traditional society. This is what characterises urban life in Kenya today." (Munyoki (1991), p.76. Look also: Warren, C.A.B. (1977) Socio-biology: Change and Continuity, Connecticut, pp.318.)

Behaviour

(i) ... and behaviour change
"Because of anomie, our people today, especially in the urban areas are lacking in moral uprightness. Tribal customs and ethnic codes that used to regulate people's behaviour are non-existent in the urban areas. Another factor that erodes morality in the urban areas is the fact that the vacuum left by the erosion of traditional values has been filled by love for money and naked materialism. (...) The result is a terrible degeneration, a lack of morality that was never known before." (Turnbull, C.M. (1962), p.76)

(ii) ... and the development of becoming a society of individualists
"Modern change has brought many individuals in Africa into situations entirely unknown in traditional life or for which that life offers no relevant preparation.(...) The individual "is posed between two positions: the traditional solidarity which supplied for him land, customs, ethics, rites of passage, customary law, religious participation and a historical depth; and a modern way of life which for him has not yet acquired any solidarity." (Mbiti, J.S. (1965), p.219)

(iii) ... and back to the roots
"Modern change also brings cultural problems in Africa. More and more educated Africans are realising that this change has alienated them from their traditional cultural roots without giving them a satisfactory substitute. This realisation has produced an increasing search for African culture from the traditional solidarity, but making attempts to bring it into the picture of the modern world." (Mbiti, J.S. (1965), p.227)

(iv) The family and the power in determining the behaviour
"The family still has the power in determining the behaviour of its members. This re-emphasises the point the the greatest strength the rural communities have to contribute to the fight against AIDS is the extended family system. The family must be counselled. Once counselled, the family can influence the behaviour of its members or one of its members, in a way which is culturally and mutually acceptable." (Chaava,T. (1990), p.86)

(v) Change of sexual behaviour in expectation of ceremonies at wedding-party
"...at wedding ceremonies, whereas people used to stay over night and have sex with several partners, people now tend to stay in the public gathering. A party is considered good if there is good food and drink, not because it offers chances for promiscuity." (in: A Review Report of CAFOD/Joint Funding Scheme AIDS

Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.38)

Children

-> Family
-> Immortality
-> Marriage
-> Orphans

Counselling

(i) the traditional way of ...
"Traditionally, counselling services were not provided by formally trained professionals but by elders within the family and the community. Old people were seen as "wise" men and women who had acquired a lot of education through initiation rites, community activities, religious experiences as well as practical experiences gained during one's life." (Munyoki,S. (1991): Counselling of HIV Positive/ AIDS Victims: The "Worried Well" and the bereaved, in: African Urban Quarterly, Vol. 6, No.1+2, p.75)

(ii) "Since these people had lived for many years they were seen as people who had acquired a lot of education that they could pass on to young through informal education and different methods of socialisation. In addition to educating and socialising the young, they also provided counselling both on a daily basis a well as during times of crises. Jomo Kenyatta talks about the role played by grand parents, parents, uncles and aunts, among others, in the education and counselling of members of a family as well as those of a community." (Kenyatta, J. (1965): Facing Mount Kenya, New York. p.75)

(iii) "Knowledge was passed on others through such methods as initiation rites and apprenticeship while counselling took place in the evening by fireside outside the house, through riddles, stories and proverbs, among others, for men, while women received their counselling services also in the evenings but inside the houses usually after the evening meal." (Mbiti, J.S. (1965): African Religion and Philosophy, New York. p.75)

(iv) "The typical African family is extended and is traditionally caring. Family links are tight. In all other forms of illness the family usually meets to consult each other before the medical profession is consulted." Kalibala,S.; Kaleeba,N. (1989): AIDS and Community-based Care in Uganda: the AIDS support organisation, TASO; in: AIDS CARE, Vol.1,No.2, p.174)

-> Preburial
-> Spiritual Life

Death

"There is an universal belief in Africa that death is not the end of existence, but a transition to spiritual life." (Knappert, J. (1990), p.64)

Dying

"Most people accept dying of old age as the normal, unavoidable conclusion of a busy, long life. (...) As for infant mortality, which still takes a heavy toll in most parts of Africa, all people known that there is a price to pay for life: one must die so that his brothers may live. (...) When people die in middle age, or worse, in the flower of youth, that is reason for serious concern that something is wrong in the relations between this world and the other one." (Knappert, J. (1990), p.64)

Family

The lost of social relations in the "modern" separated ...
"One of the most serious problems precipitated by city life in Africa is the situation which forced the men to work in towns while their wives and children remain in the country. (...) This geographical separation of families creates great strains on the emotional, psychological, sexual and marital life of husband and wife. In addition, the children grow up without a father at home, so that their image of the father is simply

someone existing in a distant town (...) and comes home once a year or every two years." (Mbiti, J.S. (1965), p.226)

-> Behaviour (iv)

Health

"The belief that ill health and mortality are caused not by natural factors but by spiritual powers is universal in Africa. Early death is caused by spirits or by God." (Knappert, J. (1990), p.64)

"Of course it is known in Africa that most diseases have natural causes. The questions, why only some of the people are being affected or why some people die young others old, let many people to conclude: "misfortune is an evil spirit. (...) Spirit is an invisible being with a will, it can think and choose its victim (...)." (Knappert, J. (1990), p.118)

Immortality

... and the need to born children
"This concept of personal immortality should help us to understand the religious significance of marriage in African societies. Unless a person has close relatives to remember him when he has physically died, then he is nobody and simply vanishes out of human existence like a flame when it is extinguished. Therefore it is a duty, religious and ontological, for everyone to get married; and if a man has no children or only daughters, he finds another wife so that through her, children (or sons) may be born who would survive him and keep him (with the other living-dead of the family) in personal immortality. Procreation is the absolute way of insuring that a person is not cut off from personal immortality." (Mbiti, J.S. (1965): African Religion and Philosophy, New York., p.26)

-> Women (ii)

Jok

"Jok is one of the most truly African concepts of the divine. (...) Jok is God and the spirit, the gods, the holy ghost, the beings from the other world. It can be vague and precise, good or frightening, beneficent or dangerous, One or a multitude, legion. (...) This word incorporates all the contradictory ideas of the spiritual beings which in the mind of Europeans must be kept carefully separated. Jok is the unified spirit of God and the gods, personal and impersonal, local and omnipresent." (Knappert, J. (1990), p.126)

-> Spiritual Life

Marriage

... and the need to born a son
In most African tribes, indeed in all patrilinear tribes which comprise the vast majority of tribal structures in Africa, the bride becomes part of her husband's clan (exactly as under Roman law) (...) in East Africa polygamy is still legal: a man may have many wives, while a woman may have only one husband. The basis of this difference is the need to produce sons, so that the father of a patrilineal family will not die without heirs to sacrifice regularly for his spirit. The clan lives as long as its male ancestors live, and they, the spirits, can only live as long as their sons and grandsons offer sacrifices regularly: the body is fed by the hands. (Knappert, J. (1990): The Aquarian Guide to African Methodology, Wellingborough, p.153)

-> Behavioural Change (v)

Mubi

AIDS Synonym, Kiswahili, East-Africa: "robber"

Mukenewa

AIDS Synonym, Uganda: "this problem make me poor"

Orphans

(i)
"The community, and especially close relatives have demonstrated great potential in the assistance of orphans in particular. After the death of a parent or both parents the

community takes it upon itself to care for orphans and bring them up in their own homes. Orphans are rarely deserted completely. In this respect the typical African community represents a major asset in AIDS care." (Kalibala,S.; Kaleeba,N. (1989): AIDS and Community-based Care in Uganda: the AIDS support organisation, TASO; in: AIDS CARE, Vol.1,No.2, p.174)

(ii)
"In Uganda it is traditional for relatives to adopt children whose parents have both died. In recent years, however, some relatives have reject children orphaned by AIDS because they do not understand how the disease is spread and are afraid of contacting it themselves. In some communities the traditional system of adoption has broken down because so many adults have died that the few surviving relatives are simply unable to bear the burden of caring for large numbers of young children." (Hampton, J. (1991), p. 18)

Philosophy

... of living and dying
"African people nothing sorrowful happens by 'accident' or 'chance' it must all be 'caused' by some agent (either human or spiritual)." (Mbiti, J.S. (1965), p.215)

Preburial

Cultural implications in preburial counselling
"At death the counselling team provides preburial counselling in which cultural implications of the AIDS patient's death are explored." (Chaava,T. (1990), p.84)

Rural Life

-> Anomie
-> Behaviour
-> Spiritual Life (ii)

Sex

(i) social use of ...
"It is perhaps the religious attitude towards sex which has produced the social use of sex. In African societies, the kinship system involves, among other things, relationships in which physical avoidance between given individuals is carefully observed." (eg. man - mother in law) (...) "On the other hand, there is the opposite 'joking relationship', in which people are free and obliged not only to mix socially but to be in physical contact which may involve free or easier sexual intercourse outside the immediate husband and wife. There are areas where sex is used as an expression of hospitality. This means that when a man visits another, the custom is for the host to give his wife (or daughter or sister) to the guest so that the two can sleep together. In other societies, brothers have sexual rights to the wives of their brothers (...). (Mbiti, J.S. (1965): African Religion and Philosophy, New York., p.147)

(ii) ... as ritual intercourse also in the mourning phase
"Some of the primitive traditions carried to date although varied, include ritual intercourse on the third day after birth of a baby girl and on the fourth day of a baby boy. This has been done in deiregard of any problems that might have occurred during delivery.
There is also sexual intercourse during funerals. Among Maasai for instance, wives of men who were initiated at ago, could have sex with any man who was a fellow initiate. All he had to do was plant a spear in front of the farmer's house.
The most notorious rape if it does occur, is that as among the Luo where during the period of mourning when a woman and the rite of inheritance known as ter or lako performed. In this case she is given a "new" husband to have sex with." (Ohito Aol, in: The Standard, Keny, 08.05.94, p.9)[153]

-> Women (i)

Slim

AIDS Synonym, Rakai-District, Uganda: "this problem eats me"

Society

Reaction of the Society by HIV/AIDS

[153]Maasai and Luo are tribes living in the western part of Kenya.

"In the city, Aids has tended to identify mainly with slums where cheap sex and illicit brews make an explosive combination." ("Aids: Anonymity does not help", in: The Standard, Kenya, 04.05.94, p.18)

Spiritual Life

(i) ... in relation to the urbanisation
"So long as people appreciate and even idolise the traditional present and past, this religiosity whether recognised as such or not will continue to enjoy a comfortable and privileged place in the emotions of African peoples. The ritual and ceremonial form will decrease as more and more people become urbanised, but their content in form of belief will linger on for a considerable number of generations. Belief dies more slowly than practice (...)." (Mbiti, J.S. (1965), p.274)

(ii) ... and the chance in rural areas and the need in difficult situations of life
"So also, however vaguely, the belief in God will linger on in towns and villages, even if acts of worship will increasingly become difficult, irregular and cultistic instead of being public, corporate and spontaneous." (Mbiti, J.S. (1965), p.274)

(iii) ... as part of counselling
"In counselling patients who have AIDS the counsellor also emphasises the quality and meaning of life. The fact that the suffering might be long and the question of life after death precipitate 'pastoral' counselling in many cases. Most patients accept the concept of 'spiritual' life. Patients who have or find faith, in terms of personal assurance of continuity of life after death, tend to show better acceptance of their last days and tend to face death more bravely than those who do not. Sharing spiritual concepts is not offensive in the rural environment (...)" (Chaava,T. (1990), p.85)

-> Jok

Talking

(i) ... about private issues in western and African culture
"However, one needs to remember that while group counselling may work smoothly in preventive counselling involving such groups as prostitutes, students and prisoners, this would not necessarily be the case with counselling of AIDS victims or the bereaved. This is because most Africans may find it difficult to talk about their sickness or death of family members in the presence of strangers. Most Africans are likely to find these issues too sensitive and private to discuss openly with people they are not close to" (Munyoki,S. (1991), p.81)

(ii) ... with relatives
"Often the family has suspicion of the diagnosis but cannot face bringing this confirmation into the open." (Kalibala,S.; Kaleeba,N. (1989), p.174)

Urban Life

-> Anomie
-> Behaviour
-> Spiritual Life

Women

(i) ...and her influence in sexual behaviour
"A woman's view and decisions are not as influential as a man's. It is usually the man who suggests having sex. Refusal of sex by a wife may result in her husband divorcing her or leaving home. It is difficult for a woman to insist that her husband wear a condom. He may respond by finding another woman. A man is often reluctant to admit that he is, or may be, HIV-positive." (in: A Review Report of CAFOD/Joint Funding Scheme AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.25

(ii) ... and the need of pregnancy
"In some tribes, if a woman dies childless there wil be no ceremonial burial. Women are, therefore, under pressure to become pregnant and prove themselves productive." (in: A Review Report of CAFOD/Joint Funding Scheme

AIDS Projects in Kenya and Uganda, prepared for the ODA Joint Funding Scheme in March 1994, p.25)

Annex V

List of Addresses of contacted Organisations

Aber Community AIDS Project	(ACAP), Dr. Drake Adupa, Project Manager Pope John's 23rd Hospital P.O.Box 310, Lira, Uganda
AMREF	African Medical Research Foundation Wilson Airport, P.O.Box, Nairobi, Kenya
Diocesan AIDS Commission	Paul Bateeze, Development Coordinator Diocese of Jinja, Rubaga-Hill P.O.Box 673, Jinja, Uganda, T: 043-22388
Hospice Uganda	Dr. Anne Merriman P.O.Box 7757, Kampala, Uganda, T: 256 41 267 488 Tank Hill Road, Upper Kisugu Close, Plot 1304
Kitovu Hospital	Dr. Maura Lynch, Medical Superintendent Sr. Ursula Sharpe, Patient Care & Mobil Unit Sr. Kay, Pastoral Care & Counselling Sr. Davnet, Laboratory, Sr. Helen, Pharmacy P.O.Box 413, Masaka, Uganda, T: 00-256-481-20097
London Lighthouse	Ciran McKinney, Community Services 111-117, Lancaster Road, London W11, 1QT Great Britain, T: 0041-71-7921200
Nsambya Hospital	Dr. Miriam Duggan, Home Care/Mobile Unit Francis Asiimwe (Counsellor) Christine Namutebi (Registered Nurse) P.O.Box 7146, Kampala, Uganda, FAX 00-256-41.510324
St. Christopher's Hospice	51-59, Lawrie Park Road, Sydenham, London SI 26,6DZ, Great Britain, T: 0044-17789252
St. Joseph´s Hospital, Kitgum	Dr. Adolph Diefenhardt P.O.Box 6785, Kampala, Uganda
TASO	Mrs. Noeline Kaleeba, Director, T: 25 00 32 The AIDS Support Organisation P.O.Box 10443, Kampala, Uganda, T: 23 11 38, FAX 25 19 82 Mr. Charles R. Kasozi, Counsellor Trainer, Mrs. Rachel Richardson, Orphan's Programme TASO Trainingscenter, P.O.Box 10443, Kampala Plot 21, Kitante Road, T: 27 17 52 Head of TASO AIDS Center and Day Care, Kampala-Mulago, T: 53 0034
UCMB	Uganda Catholic Medical Bureau David Kirunda, National AIDS Co-ordinator P.O.Box 2886, Kampala, Uganda, T: 00-256-41.268175, FAX 00-256-41.268104

Annex VI

Terms of Reference

1. Literature study of the hospice approach and experiences in both Western and developing countries.

2. Inventory different approaches of care and counselling for HIV/AIDS patients and their families, especially in the situation of weak social support structures (urban areas) or absent coping mechanism (whole families and communities affected by the epidemic).
   Inventory will encompass work of the churches, NGOs and self-help groups, especially in the urban areas:

   Uganda:
   - UCMB, Kampala
   - UCOBAC, Kampala
   - Nsambya Hospital, Kampala
   - TASO, Kampala
   - Kitovu Hospital, Masaka
   - Virika Hospital, Fort Portal

   The inventory will be conducted by interviews with the key persons and in Uganda also by field visits of the AIDS patients together with (home based) care teams.

3. Analysis and syntheses of above mentioned literature and field experiences.

4. Formulation of a number of options for comprehensive care of HIV/AIDS patients and their families during the different stages of the disease, in view of size of the pandemic, limited resources and weak support structure in Africa.

5. Defining role of different actors in those options: self-help groups, churches, NGOs, funding agencies.

Annex VII

Annex VIII

Culture as opposed to HIV/AIDS Prevention

by Francis Assiime, Counsellor Supervisor, Home Care, Nsambya Hospital, Kampala

Many people have either heard, talked, written about or experienced HIV/AIDS. Most people now are aware of its modes of transmission and how to prevent it. On prevention, most people are of the view that there is a need to give sex education to the youth and to carry out "Behavioural Change programmes to different communities which is okay but who is to give it.

Lets take a look at sex and HIV/AIDS. Sex is defined as the quality of being male or female but is commonly taken as the act of having sexual intercourse (the coitus) in along man's language. This quality of life plays a major role in the continuity of society to future generation: Procreation. It also binds and strengthens the union of the married couples and their two clans whereby one offers him/herself wholly to the other thus becoming one.

Secondly this quality of life is secret hence not talked of in public in most societies. Each normal grown up person is expected to play an active role in this secret act.

However in "Modern" Society, sex or sexual intercourse has taken on a different trend and people have different attitudes towards it.

Some see it on a source of evil like HIV/AIDS, unwanted pregnancies and STDs.
Some especially the youth see sex as an act of self worthiness in society. It is a way to prove ones man/womanhood. For the youth it is experimental.
Some play sex due to economic hardships while others it proves their economic status hence become commercial and proof for riches respect.
Yet others see it as a source of "pleasure": "How can you enjoy life without playing sex?", one youth challenged me.
For others play sex due to the prevailing "environment/culture", say "vegetarian and non-vegetarian" culture at Makarere University * is one who fears men/women and the one who is able to prove that he can approach men/women with courage respectively. This encourages some who could have abstained from sex to play sex just to fit in society.

Culturally, sex education is given to girls and boys when they are preparing to get married and not before. This is because sex was talked of in a bedroom not in public. So while we forget the youth and sexually active groups, a feel that there is a need to give the same to the old generation especially the parents who will in turn give it to their children. Parents need to be empowered. In the same way cultural heads need to be sensitised and given information on the ways of HIV/AIDS infection thus be given behavioural change education. This will being about the change in attitudes towards sex.

First case study

Jane came to attend a gynaecology clinic due to infertility. The doctor referred her to a counsellor for HIV/AIDS counselling later on blood testing. The test was done and came out to be HIV positive. She had told me that she abandoned her first husband since they could not produce yet in her culture she wait be accorded a burial if she dies without producing. She got married to another man but still failed to produce yet she wants a decent burial and to be recognised in her society as barrenness is seen as a curse. We discussed further about the effects of being HIV positive and how one should behave and care for him/herself so as to his/her life. We also discussed about avoiding sex that might result into pregnancy thus weakening her move but she became adamant on this issue due to her cultural beliefs. Pregnancy proves one's worth in society and in the end a good send off.

* Makerere University, the only one in Uganda, is based in Kampala

Second case study

Joseph is from Kabale south western part of Uganda. He used to commute to Kampala where he did his retail/grocery shopping. He was married with two children. The youngest died when he was three month old. His wife later died after a long illness. He suspected HIV/AIDS thought his relation believed that his family was bewitched by someone opposed by his progressive character.

While in Kampala he came to me for guidance and blood testing if possible for HIV. After present counselling the blood was taken off which after a test was found HIV-positive. and he accepted it and promised to take up a positive living.so that he can live a lot longer while he prepared for his only remaining child. However he found a different story at home. His parents were advising him to take up the sister of his later wife so as not to break the relationship with the other family/clan. Since he thought it too early to reveal his sero status he convincingly told them that he would think about it. After a month the clan elders came in to convince him take the girl. He hactatingly accepted while he prepared to come to Kampala for guidance. However as he went for an evening visit to a friend, the elder organised and brought in the girl. On reaching home at night he was greeted with chants from a crowd. And there he was. The girl as in but he took his stand and told the girl the truth which she did not believe and due to fear for elders choice she can not go away. Fearing to infect the girl, he decided to abandon the family and the girl. He now lives in Kampala in a rented house which not only expensive for him but also hinders him form his original plan of planning for his only child.

These two and many other examples are indicators of how culture is hindering the fight against HIV/AIDS. This shows that there is a need to sentice the elders about the dangers of HIV/AIDS and their cultural attitudes towards sex. So while we give sex education and behaviour change programmes lets not forget the parents and clan elders who can in fact give the same to their children and societies respectively. Even the advocate of a condom will find their efforts are futile until the cultural attitudes towards sex are changed. Condom is against procreation hence against society's continuation.

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