AIDS Orphans and Vulnerable Children Needs Assessment

FHI Home Based Care Programme

Bungoma District

Western Kenya

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Operational Definitions

For the purpose of this research the following definitions are necessary:

AOVC – (Aids Orphans and Vulnerable Children) A child under the age of 18 who has lost his/her mother or father to HIV/AIDS or is living with a parent who is sick due to HIV/AIDS.

Child - A person who is aged between 0 and 18 years (NASCOP Kenya. 2002)

Healthy – At time of interview, child is not sick and has not experienced weight loss, weakness or diarrhoea continually in the past three months.

Household - A group of people who live in the same dwelling and eat meals together (UNAIDS 1999)

Carer - That person (Mother, Father, Brother, Sister, Grandparent, Relation, Neighbour or Friend) who takes care of the child on a daily basis at the time of the study.

Client – A person who is showing HIV/AIDS related signs and symptoms whether they have been tested or not and is visited by a community health worker on a regular basis.

Next Birth Child – The child living in the household with the closest next birthday to the day of the interview, considered on the basis of a specific date. If two children have the closest next birthday falling in the same month and the specific date is not known, both children are to be included for interview.

Head of the Household – That person who runs the household

Balanced Diet - A daily diet which comprises of at least three meals containing a proportional balance of proteins, carbohydrates, vegetables and fruit.

Poor Diet - A daily diet, which comprises of less than three meals a day and which is lacking in one more of the components that make up a balanced diet.

Negative change in living standards – Where the standards of the household have changed for the worse over the past year, in terms of income and living standards.

Positive change in living standards – Where the standards of the household have changed for the better over the past year, in terms of income and living standards.

List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AOVC	Aids Orphans and Vulnerable Children
CACC	Constituency AIDS Control Committee
CBO	Community Based Organisation
CHW	Community Health Worker
DACC	District AIDS Control Committee
DPHO	District Public Health Officer
DPHN	District Public Health Nurse
DMOH	District Minister of Health
GOK	Government of Kenya
HBC	Home Based Care
HIV	Human Immunodeficiency virus
ICROSS	International Community for the Relief of Starvation and Suffering
FGD	Focus Group Discussion
MOH	Ministry of Health
NACC	National AIDS Control Committee
NGO	Non Governmental Organisation
PACC	Provincial AIDS Control Committee
PLWA	People Living With AIDS
STD	Sexually Transmitted Disease
TOT	Trainer of Trainers
VCT	Voluntary Counselling and testing

Literary Review

It has been estimated that 16 million children have now been orphaned by HIV/AIDS worldwide, 95% of who live in sub Saharan Africa. (Progress of Nations 1999.) These figures not only represent a vast human tragedy, they also underpin a crisis that is challenging the social, educational and economic structure of African countries. The crisis is not estimated to peak until the year 2010 and its impact is being felt throughout communities, societies and educational systems.

'Millions of children and adolescents have already been orphaned by HIV/Aids; tens of millions more will lose one or both parents to the pandemic over the next 10 years. The social and economic impact of AIDS will lead to the rights of hundreds of millions more children being violated or threatened.' (Discussion paper Principles to guide programming for Orphans and other vulnerable children IIEP 2001.)

UNAIDS define AIDS orphans as 'children who lose their mother to AIDS before reaching the age of 15. Some of these children have also lost, or will later lose, their father to AIDS.' (UNICEF1999.p5) This definition of orphan does not include those children who have only lost their fathers to HIV/AIDS. Monk notes that, 'by excluding children who have lost their father, young people between the ages of 15 and 18, and non-orphaned children living in households that foster orphans, the UNAIDS definition fails to recognise many of the children rendered vulnerable by the pandemic….and that in reality the figures should be multiplied by four. (Monk. AFXB. 2001.p7) It is also worth considering the notion, that given the nature of the disease and the number of children caring for sick parents, that children are often in effect orphans before losing a parent. The Government of Kenya defines the term AIDS orphan as " a child under the age of 15 who has lost their mother to AIDS." They estimate that, "the cumulative number of AIDS deaths in Kenya will have increased from 1.5 million in 2001 to 2.6 million by 2005." This development will result in an increase in the number of orphans in Kenya, rising from 0.5 million in 1999 to 1.5 million by the year 2005. (AIDS in Kenya sixth edition 2001 MOH. NASCOP Kenya.)

"Research in developing countries on the socio-economic impacts of HIV/AIDS on households has shown the main impacts to be social, psychological and economic." (UNAIDS.1999) Whilst there has been increased attention given to the socio – economic

dimensions of AIDS on children, there has been limited research into the psychosocial impact of the epidemic. However, research does indicate that psychological impact can manifest itself in a number of ways and children orphaned by AIDS show an 'increase in stress and trauma,' feel 'hopeless or angry' and are more prone to depression. (Foster/Williamson 2000.pS282)

Whilst there is a need to address the specific psychosocial needs of AOVC, it is important that they are assessed in relation to all aspects of a child's life. This too must be considered within the normalcy range of childhood in a particular socio- economic and geographical context. "HIV affected children have many of the same needs as other children – nutrition, exercise, education, love and affection. Beyond these, affected and infected children, whether orphaned or not, may have special needs such as counselling, medical treatment, vocational training and encouragement of self- reliance. A child's development is dependent on all of these needs and each must be adequately addressed." (Kumar/Pani.2002)

Psychosocial needs differ according social and cultural beliefs and contexts. It is therefore necessary to assess specific community perceptions as to the needs of children orphaned or made vulnerable by the disease. In order to understand the circumstances of communities, existing coping mechanisms must be assessed so as to extend programmes and utilise existing support mechanisms through increased communication. The circumstances of AOVC need be addressed in a culturally sympathetic and realistic manner in order to make programmes sustainable. The Kenya National HIV/AIDS Strategic Plan 2000-2005 (NACC October 2000 GOK.) in conjunction with the Kenya AIDS NGO Consortium, advocate for the strengthening of Home Based Care Programmes and improved collaboration amongst health care providers, communities and families through better training, mobilisation and sensitisation in order to guarantee that the human rights of all Kenyans will be respected.

A workshop in Zimbabwe, involving partners from East and Southern Africa aimed to assess the proliferation and effectiveness of OVC community based initiatives. They concluded that whilst the community responses to the needs of AOVC were proliferating, there were no networks to assist in their development. These 'organic' and informal activities of community members were considered vital in strengthening their capacity to

cope. However, key workshop conclusions suggested that stakeholders must be aware of their "respective 'niche roles', act appropriately and work together to support community mechanisms. Policy/resource organisations should make greater commitments to the development of supportive OVC policy and commit more funding through intermediaries." (FACT. Zimababwe.2002)

The IMPACT, Home Based Care Programme works in the Bungoma District of Western Kenya. It has been estimated that in the year 2000, 3,882 people were infected with HIV/AIDS in urban areas of the district and 36, 326 in rural areas. In 2000 the HIV prevalence rate was at 9% and it is now estimated to be on the rise and between 25-35% (AIDS in Kenya sixth edition 2001 MOH. NASCOP Kenya.) This increase in infection has given rise to an increased number of AOVC in the area and it is estimated that one in three households in the area will be infected or affected by HIV/AIDS. The total population of the Bungoma District in 1999 was 876,491 and the total number living in the area under the age of 24 was 447,286. Thus 51% of the population is under the age of 24. (National Population census.1999)

Purpose of Study

The purpose of this study is to understand community perceptions about the existing HBC programme and to gather information about the needs and circumstances of AOVC in communities in Bungoma, Webuye and Nzoia districts of Western Kenya. Knowledge about the existing community coping mechanisms in the area will also guide programming for the provision of support in the psychosocial care of AOVC. Whilst its main priority is the assessment of the needs of children directly affected by HIV/AIDS, it is necessary to consider the needs of all children in the area.

Objectives:

- To identify gaps, institutional or otherwise that may hinder implementation, drawing on the experience of HBC programmes.
- To record the number of households in the HBC programme where there are AOVC currently living and needing care.

- To develop links with DMOH/CACC's, FHI, NGO's and CBO's involved in AOVC and HBC in order to build support for the programme, draw on similar and complimentary experiences and identify community coping mechanisms that can be strengthened.
- To establish an understanding of existing community Knowledge, Attitudes and Practices (KAP) of the psychosocial needs of AOVC.
- To use data to prioritise the needs of AOVC whilst acknowledging the needs of all children, so as to guide curriculum development and training.

METHODOLOGY

The methods used were both participatory and observational. The survey was conducted using the following methods:

1. **Focus Group Discussions**
2. **Questionnaires**
3. **Interviews with key informants**
4. **Researcher's observations.**

1. Focus group discussions. (FGD)

These involved:

i) Community leaders
ii) PLWA (People Living With HIV/Aids)
iii) Women's Groups
iv) DMOH, DPHO,DPHN,NGO's and CBO's

The discussions were conducted in groups of between eight and ten people. The participants were chosen using the local knowledge of the Field Officers. Groups were collaborated according to geographical sites and status. The discussions lasted approximately one and a half hours and were grouped as follows:

One group of PLWA - Women
One Group of PLWA - Mixed.
One Group of Community Leaders - Men
One Group of Community Leaders/ DMOH/ District Hospital staff – Mixed
One Group of NGO's /CBO's /Self help Groups – Mixed
One Group of Women's /Self help Groups – Women

The discussions were based around similar questions for all the groups but were adapted for discussions with PLWA. Questions were open-ended and responses categorised. Participants were asked to comment on the Home Based Care (HBC) Programme, its impact and ways in which it could be improved upon. Perceptions were gathered as to what the community expected and wanted from the HBC programme. Participants were asked for their perceptions as to the needs of AOVC (Aids Orphans and Vulnerable Children) in the area and what support strategies and coping mechanisms were in place in the community to deal with these needs. Participants were then asked how they thought the community could be mobilised to accommodate the nutritional, social and economic needs of AOVC. The issue of stigma and discrimination was addressed.

The discussions with PLWA took on a similar format but involved more personal questions concerning their fears and ways in which they had prepared their children for their death. The FGD's gave rise to qualitative data.

2. Questionnaires.

Two qualitative perception based questionnaires were used for the study.

i) Carers of children questionnaires were structured, standardised and interviewer completed.

ii) Trainers of Trainers Questionnaires were unstructured and self completed.

The questionnaires aimed to gather a representative proportion of the population's perception of the needs of children and therefore do not represent the *actual* needs of children. However, perceptions, attitudes and responses of those interviewed are based on cultural determinants, beliefs and social behaviour and are representative of the perceived needs of children, which, in themselves are as evident as their *actual* needs.

The carers of children questionnaires aimed to determine the social, educational, nutritional, emotional, behavioural and economic needs of children in the area. The questionnaires were administered in households where there were no signs of HIV/AIDS (control) and in households where there were known to be PLWA (study.)

The Trainers of Trainers questionnaires aimed to determine the attitudes, perceptions and responses of those involved in the HBC programme about the needs of children living in households with PLWA and how they differ from those not affected. It was hoped that the responses would contribute to a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis of the existing HBC programme.

Carers of Children questionnaires.

Type. Questions were set choice, including single and multi answer questions, intended to cover classification, behaviour and attitudes. The first part referred to the household make up and educational and economic status of parents. The same information was asked of the carer of the children, if different from the parent. The second part of the questionnaire referred to the child. The information about the child included:

i) Basic health in the past three months and at the time of the interview.

ii) Basic nutrition i.e. number of meals per day and their type. Type was categorised into balanced and poor. Diet was categorised as balanced if the child received three or more meals a day and their content included a balance of protein, vegetables, carbohydrates and fruit. Diet was categorised as poor if the child received less than 3 meals a day and the content was lacking in one or more of the components.

iii) Education, level, number of days in school and expenses paid by whom.

iv) Emotional and behavioural, including any experiences of discrimination, HIV disclosure, exploitation or abuse, signs of anger or anxiety etc.

v) Life skills.

vi) Assistance from the community.

vii) Number of friends and hours of play.

viii) Manual labour and hours per week.

Implementation

Stratified sampling was used to select the study households. All households with PLWA visited by Community Health Workers in the HBC programme were interviewed. The existing knowledge of the CHWs was used. Households where the client had deceased were also visited. A total of 300 study households were visited.

Simple random sampling was used to select control households. Households were visited within the same geographical area as study households and were chosen by the CHW working in the sampling point. Control households had no PLWA present. A total of 200 control households were visited.

Children about whom the carer was interviewed were picked at random, citing the next birth child of the household.

Training

79 Community Health Workers were trained in the implementation of the questionnaires. Training took place on three separate days at the three sites, Bungoma, Nzoia and Webuye. Trainers of Trainers (TOT) were present and a Swahili and Bukusu interpreter was used. The training involved introduction and instructions, the translation of the questionnaire in groups, role-play in groups of 6 with one ToT per group, group presentations, comments and discussion.

Questionnaires were conducted in Swahili or Bukusu and completed in Swahili or English. Questionnaires were pre tested in the field and individually checked by the researcher. Where there were misunderstandings, CHW's were retrained individually by the researcher. Spot checks were made in the field by the researcher once the research was complete. Where questionnaires were incomplete, misunderstood or invalid, they were rendered useless for the purposes of analysis.

Method of analysis

Questionnaires were age and sex stratified and a comparison was drawn up between children living in households with PLWA (study) and children living in households where there was no HIV/AIDS (control.) The control group was represented by a 75% sample, a total of 178 completed questionnaires. The study group comprised a total of 250 completed questionnaires.

ii) Trainers of Trainers questionnaires

The questions were unstructured, using open – ended questions to produce qualitative data. The questions referred to the HBC programme and ways in which it could be improved upon, citing the problems being encountered. Perceptions of the needs of

AOVC were covered and the level of training existing and needed was assessed. Perceptions of the training level of CHW's in the psychosocial needs of AOVC were also addressed and the existing coping mechanisms within the community noted. Questionnaires were completed by 24 TOT's and returned to the researcher.

3. Interviews with key informants

Five CHW's were key informants, giving their views on, the efficacy of CHW's to recognise the needs of AOVC in households with PLWA, the strengths and weaknesses of the HBC and suggested ways forward to accommodate the needs of AOVC. Capabilities of CHW's to extend the HBC programme to address the needs of AOVC were addressed and further training was discussed.

4. Researcher's observations

Visits to patients were conducted after the research was complete.

The researcher spent a day with each Field Officer (3) visiting clients, health centres and hospitals. The researcher also spent a day with two CHW's, visiting clients, children of PLWA and attending funerals. Other key informants included Field Officers and the Project Manager. The researcher also referenced notes of past meetings and quarterly reports of the HBC programme to identify any evidence of obstacles to the service provision.

FINDINGS

1. Focus Group Discussions.

a) PLWA - A total of twenty PLWA took part in the discussions divided into two groups by site and sex. One group comprised ten women and the other four men and six women.

Views on the HBC Programme

The general feeling was that the HBC programme had enhanced the lives of PLWA. The provision of drugs, vitamins, advice on positive living and medical care has been instrumental in the prolonging of lives and improved living conditions. Clients expressed gratitude for the support they receive from the CHW's. Some cited themselves as examples of bedridden cases whose health has improved enormously thanks to the work of ICROSS and that they have been periodically restored to a state of health, which

has enabled them to continue with household chores and work commitments. Without the work of ICROSS, many clients felt that they would be left alone to die without support and that, their life expectancy would be greatly reduced. The members of the discussion groups welcomed the chance to talk about their concerns and stated that they had not had the opportunity to do so before.

PLWA's expectations of HBC:

i) More drugs are needed in order to improve the quality of life and increase life expectancy. Drugs such as panadol were thought to be insufficient for the medical conditions that were being treated. More advanced drugs were requested.

ii) An increase in the number of weekly visits by CHW's would improve morale and the level of support.

iii) The training of the healthier PLWA in HBC is needed in order to increase awareness and the reach of the programme.

iv) Provision of food. Fruit, meat and vegetables are needed to improve the nutritional status of clients.

v) There is a need for PLWA to meet regularly and discuss their concerns and gain support from each other.

vi) Fees for schooling for the children of PLWA are needed.

vii) In some cases, CHW's to be responsible for parent's HIV disclosure to the children.

viii) The development of strategies to reduce the stigma and discrimination that is associated with HIV/AIDS.

ix) CHW's to be trained in the emotional, social and nutritional care of AOVC.

x) CHW's to be trained in the psychological needs of AOVC in order to counsel children of PLWA.

PLWA perceptions of the needs of AOVC:

i) Food

ii) School Fees

iii) Love and affection

iv) Clothing

v) Life skills training such as personal hygiene, nutrition, land inheritance rights, knowledge of children's rights, education in safe sexual behaviour and ways in which to access local services.

vi) Income generating skills i.e. improve children's efficacy in self-reliance and provide them with the mechanisms and skills that will enable them to support themselves after the parent has died.

vii) Referral network within the community so that the child is monitored when parent is bedridden or has deceased.

viii) Counselling and HIV education from the moment the parent becomes sick so that the child (depending on age), is able to better understand the step by step process of HIV and acceptance and preparation for death is eased.

Existing Community Coping Mechanisms:

All members of the PLWA discussions stated that they were not aware of any support mechanisms available to them within the community to help care for their children, either whilst they were alive or after their death. The feeling was that the extended family network is not coping with the scale of the problem. Despite the predominant community desire to help, limited resources, increased poverty both locally and nationally and a reduction in the number of adults within the community due to HIV/AIDS means that the majority of families within the area are affected in some way by the epidemic. This means that the extended family is not able to assist AOVC either financially or emotionally on a regular or sustainable basis. Where there is no extended family, women and children particularly are being left alone. The women stated that the stigma and discrimination that they and their children received from their husband's families meant that they were in many cases rejected from their homes and were the subjects of property grabbing by their husbands' relations and were left isolated and ostracised from the community. In a number of cases, clients had lost contact with their children, they had left home and gone to the streets. Many clients stated that the worry and concern they have for their children both now and for the future causes their health to deteriorate. Many of the women in the group were unaware of their human rights. Five out of the ten women experienced land and property inheritance abuse and were unaware of their rights in issues such as wife inheritance. They were also unaware of the rights of their children.

PLWA stated that they were unaware of self-help groups or CBO's in the area giving help. They felt they did not know where to go to for help and that the medical support networks such as health centres and the District hospital were too far away to access and too expensive. The CHW's were the only people who could assist them but they were limited in their knowledge of the existing structures for AOVC. The overwhelming degree of stigma and discrimination within the community hampered any attempts to assist the families of PLWA. All members of the discussion stated that the silence that surrounds HIV/AIDS was detrimental to improving the status of AOVC. All members agreed that there was a need for a community focal point to address the needs of AOVC and to reduce the social stigma associated with HIV/AIDS.

Preparation for death:

There was a mixed reaction from the participants to children knowing the HIV status of their parents. The women's group stated that they felt that it was important that their children knew their status and were prepared and counselled for their death. Three out of six men in the mixed discussion, felt that their children should not know their status, as it would increase their isolation from the community. They stated that they did not feel it was their responsibility to tell their children their status. Approximately one third of members felt that it would be emotionally and psychologically easier if the children were told by the CHW about their status and that, children's counselling and HIV education should start from the moment that they had been told. Over half of the participants stated that their children knew of their status but had not been counselled in preparation for their death. The majority of the participants felt that it was important that the children had someone to talk to about their concerns.

b) Women's Groups/NGO's/CBO's

A total of 15 people took part in two discussions, at two different sites. One group comprised seven women from CBO's and Women's Groups, the other comprised mixed sex IMPACT members NGO's and CBO's.

Views on the HBC programme:

Approximately half of the participants had not heard of ICROSS and were unaware of the work that the HBC team did. It was apparent that the majority of the members had

not met and were unaware of the work that they each did. Those that had heard of the work of the HBC programme were impressed with the care that the CHW's give PLWA.

Community expectations of HBC programme and suggested improvements:

i) Increase in medication. ICROSS to support women's groups and to open chemists so that drugs can be sold cheaply and be more accessible.
ii) ICROSS to cater for medical bills when client is hospitalised. ICROSS to liase with MOH to waver medical bills when client is unable to pay. Develop a system of cost sharing for medicines.
iii) ARV drugs to be provided to prolong life.
iv) ICROSS to provide food when the client is bedridden.
v) HBC programme to educate clients on cheaper nutrition alternatives that are locally available.
vi) Help with school fees for children of PLWA. Liase with MOE to waver expenses for AOVC.
vii) Provide counselling for AOVC.
viii) Establish a centre for AOVC for counselling, HIV education, and income generating training.
ix) Develop links with other CBO's.
x) Mobilise Church leaders to visit clients to strengthen them spiritually.

Perceptions of the needs of AOVC:

i) Food
ii) Clothing
iii) Education
iv) Medical care

Perceptions of issues that affect AOVC and differ from other children in the community:

AOVC:

i) lack adult love and attention – they are often neglected
ii) assume adult responsibility early
iii) fear visiting neighbours due to stigma

iv) are often assumed to be HIV positive

v) are isolated and lonely

vi) are more likely to be exposed to child labour and exploitation

vii) have no one to advocate for their rights

viii) need to generate income in order to survive

ix) have greater social and domestic challenges

-not aware of the basic skills of cleanliness, nutrition and socialisation

-have to care for their sick parents and watch them die over a long period of time

Existing community coping mechanisms:

The following schemes/operations are active in the area:

i) Women's Groups - providing help in cleanliness and medical care of patients and children. They are also active in developing women's empowerment and conducting group discussions for women in the community to help them to combine food and financial resources, encourage positive living and advocate for their rights.

ii) Income generating schemes

- Agricultural training to improve food security and health for children
- Dairy projects
- Bee Keeping projects
- Micro finance projects
- Knitting
- Indigenous husbandry skills

ii) Other Groups

- Church groups
- Legal Education
- Social Support Groups
- Village Banking Schemes
- Youth Education Programmes

Despite the number of existing groups and schemes within the community, the participants agreed that PLWA are often unaware of the facilities that are available to them. It was mentioned that some community leaders attempt to bring families together for support but rarely advocate the services that are available, probably due to lack of

knowledge of their existence. Participants in the discussions noted that community members were often reluctant to attend Chief's baraza's and therefore the messages conveyed at these meetings did not meet the people that needed them most. All the participants agreed that there were no support mechanisms active within the study area, which particularly targeted AOVC. The majority of participants felt that the community was willing to help AOVC but due to financial restrictions they were reluctant to become involved. They felt that the community was fighting a moral dilemma as they recognised the need for assistance but were unable to help due to their own survival needs. Some members of the discussions however, felt that the community was reluctant not only because of financial restrictions but also on account of the stigma and discrimination that is associated with HIV/AIDS.

Suggested ways in which to mobilise the community to address the social, educational and nutritional needs of AOVC:

i) Mobilisation of chiefs, village elders and church leaders
- to advocate the services existing within the community
- to reduce the stigma associated with HIV/AIDS by talking openly about the disease and those that are affected and infected.
- to take responsibility for the AOVC in their area

ii) Advocate for the acceptance of HIV/AIDS within the community and the reduction of stigma and discrimination
- Drama and music workshops
- Schools
- Churches
- Audio presentations

iii) Educate young girls about safe sexual behaviour and their rights from being inherited or becoming young brides.

iv) Provide the technology and skills to teach families about nutrition and health

v) Encourage participation in income generating schemes

vi) Encourage community sharing schemes

vii) Establish a community focal point to identify the needs of the children and create a place where the community can meet to address the needs of all children so as to reduce stigma.

viii) Mobilise schools to become more actively involved in the care of AOVC.

ix) Develop greater links with MOH and MOE in order to generate a greater awareness of the social services available that the community is entitled to.

x) Challenge expensive cultural practices such as funeral and circumcision gatherings/traditions so that the money can be spent on more pressing needs.

xi) Advocate for the need to waver medical and educational expenses for AOVC.

xii) Encourage local government, community leaders and the community at large for the need for a focal point for activities to help reduce stigma and develop community responsibility for all children in the area.

c) Community Leaders/DMOH/District Hospital staff

A total of 15 members participated in two discussions at two different sites. One group comprised 8 all male community leaders and village elders, the other group comprised women and men from the MOH and community leaders.

Views on the HBC Programme:

Participants in the discussion expressed their appreciation for the work that ICROSS Home Based Care team is doing. Members from the hospital stated that the number of patients admitted to hospital had reduced in the past year due to the work of ICROSS.

Expectations of HBC programme and suggested improvements:

i) Provision of more drugs to clients.

ii) HBC to provide food to clients.

iii) Increase visits by CHW's.

iv) Improve referral system to hospital.

v) Provide transport to improve services.

vi) Encourage local and national government to offer VCT and drugs free of charge to AIDS patients.

vii) Train CHW's in nutrition using locally available produce.

viii) Recruit and train more men as CHW's to reduce stigma.

ix) Recruit and train community leaders and village elders as CHW's.

x) Encourage community leaders and village elders to act as support for CHW's in their area.

xi) Recruit and train more youth as CHW's.

Perceptions of issues that affect AOVC and differ from other children in the community:

i) Lack of love and affection.

ii) Lack of adult attention.

iii) Lack of life skills.

iv) Lack of food and nutritional knowledge.

v) Lack of and a greater need for income generating skills.

vi) Lack of knowledge of land rights and inheritance rights.

vii) Negative attitudes from the community due to stigma.

viii) Negative treatment from relatives where there are other children in the household.

ix) Lack of funds for education.

Existing community coping mechanisms:

The Children's Department stated that they offered counselling for children and guidance on life skills. Participants stressed that the client is unaware of the service, particularly those PLWA in the rural areas where transport and communication is limited. The work of CACC was perceived as being inactive in so far as it did not reach the community level.

-Village chiefs and elders noted that there was little recognised support in the rural areas for PLWA and AOVC and that there was a need to decentralise initiatives to a more localised level, either the sub location or village level. The family network was said to be active in the support of PLWA but resources were limited and the clanship mechanisms that in the past had coped with disaster were struggling under the enormity of the situation. Village elders and chiefs were said to be active in the monitoring of AOVC and actively communicating with schools as to their needs and citing relatives to take responsibility for AOVC.

-Village elders noted that the church was instrumental in the spiritual support of the community but there was a need to increase awareness of HIV/AIDS and develop strategies to reduce stigma through its work. It was mentioned that there were a substantial number of denominations within the area who held the belief that HIV/AIDS did not exist and that it was the work of witchcraft, which was causing so many to suffer. These churches were said to be very influential in the area and detrimental to efforts to change local perceptions of HIV/AIDS.

- NGO's and CBO's were said to be active in schools, educating about safe sexual behaviour through talks and videos but there was nothing being done to accommodate the needs of AOVC or improve the lives of PLWA. Child to Child was mentioned as having been active in the area in the past but their methods had stopped being used in schools as many of the teachers who were trained had left the area. Some CBO's were cited as being ineffective.

Suggested ways in which to mobilise the community to address the social, educational and nutritional needs of AOVC:

i) Decentralise responsibility by using the status and influence of village chiefs and elders to reduce stigma and discrimination and improve support for PLWA and AOVC:

- Train leaders in HBC, nutrition and the needs of AOVC.
- Develop a referral and support network of village elders and chiefs for CHW's.
- Mobilise village elders and chiefs to visit schools to increase awareness and advocate for the needs of AOVC.
- Advocate for CACC's to appoint local administrators to take active responsibility of AOVC.
- Improve communication between, village chiefs and elders, PLWA, NGO's, CBO's, teachers, MOH and local CACC administrators by establishing AOVC committees at the sublocation level to meet on a monthly basis in order to monitor all vulnerable children in the area and decide on the way forward.
- Develop a system of recording and monitoring the number of AOVC in the area and take responsibility for addressing their needs.
- Advocate for the development of legal documentation in the form of wills or more culturally sensitive methods to safeguard the rights of AOVC.

- Develop strategies for village banking and cost sharing for AOVC and PLWA.
- Advocate the works of organisations at funerals and barazas.
- Develop income-generating schemes.
- Develop links with churches of all denominations and advocate for local leaders to lobby for a local and national policy to abolish cults and denominations that work against the fight against HIV/AIDS.
- Village chiefs and elders to scrutinise the works of CBO's in the area and only involve them if they work effectively for the good of the community

ii) Increase the involvement of schools in accommodating the needs of AOVC.

- Develop workable manual for teachers to use in schools to implement HIV education and awareness.
- Advocate for the HIV/AIDS curriculum to encompass HIV/AIDS patient management.
- Retrain teachers in Child to Child methodology so that it is active in schools in order to promote life skills, encourage parental listening and learning from children, HIV awareness and the reduction of stigma and discrimination.
- Encourage theatre and music workshops to disseminate messages.

Findings - Questionnaires for Carers of children aged between 0 – 18 years.

Control Households

A total of 200 households were visited.
A total of 178 questionnaires were valid for analysis.

Study Households

A total of 300 households were visited.
A total of 250 questionnaires were valid for analysis.

Questionnaires were rendered invalid when incomplete or misunderstood by the interviewer. 20 households in the study group visited had no children living there, they had either moved away after the death of the parent or the information about the number of children in the household was incorrect at the time of the study. The study households are representative of households in the study area with PLWA and have been systematically selected based on the knowledge of the interviewer, i.e. that they have or are regularly visiting a PLWA in the household. The control households are a non-random sample of households in the study area where there are no PLWA. The selection of these households was made by the individual interviewer and therefore has potential for bias. This potential was minimised by the selection of households within the study area where there were children living but there were no PLWA. Children were selected at random. Population characteristics within the study area vary very little, hence the size of the samples are valid.

Training standards were rigorous to minimise interview error and total survey error. Questionnaires were pre-tested and interviewers who were unable to conduct the interviews successfully were identified and retrained. Where the interviewer was again, unable to implement the questionnaire successfully due to little or no literacy skills, language barriers or poor comprehension of the intended questions, ToT's were instructed to conduct the interview. The CHW accompanied the ToT to the households. A field supervisor assisted the control of interviewer error. Spot checks were carried out in the field by the researcher post interviews. The use of many interviewers means that there was the potential for systematic differences between the results obtained by the different interviewers. Response errors have been minimised in analysis by eliminating any completed questionnaires that do not correlate with household information.

Subgroups of sample groups:

Control Total 178
Age: 0–5 years
Total: 35
Male: 19
Female: 16

Age: 6-10 years
Total: 55
Male: 27
Female: 28

Age 11-15 years
Total: 73
Male: 35
Female: 38

Age 16 – 18 years
Total: 15
Male: 8
Female: 7

Study Total 250
Age: 0-5 years
Total: 39
Male: 22
Female: 17

Age: 6-10 years
Total: 78
Male: 39
Female: 39

Age: 11-15 years
Total: 102
Male: 56
Female: 46

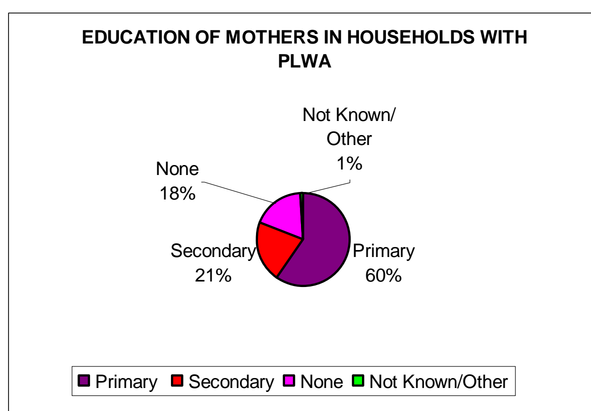
Age: 16-18 years
Total: 31
Male: 17
Female: 14

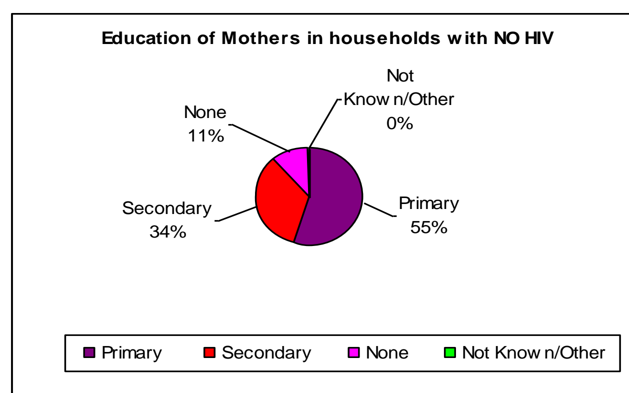
A. Household information

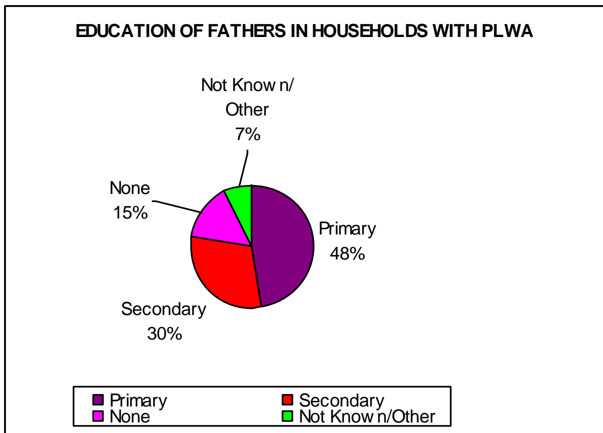
The questions aimed to establish whether there were substantial differences between the study and control groups in the following categories:

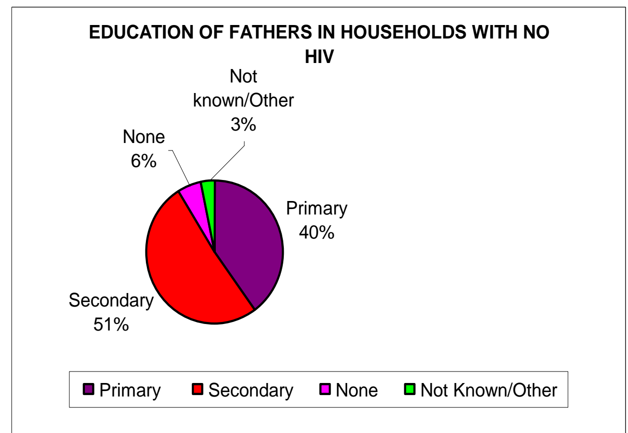
i) Education level of Mother and Father
ii) Languages spoken and written
iii) Sources of income
iv) Monthly income
v) Change in living standards
vi) HIV status/death of parents
vii) Carer of the child
viii) Carer living in household

i) What is the education level of the mother and father of the child?
In both cases and with both parents, the predominant level of education was Primary. In HH with No HIV there was a higher incidence of parents reaching secondary level 20% fathers and 13% mothers. There was a marginally higher incidence of no education in both mothers and fathers in HH with PLWA.







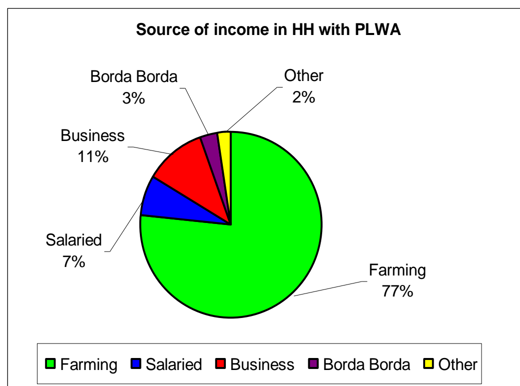


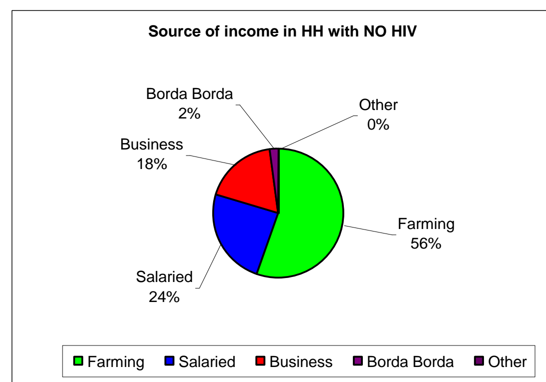
ii) What languages are written and spoken in the households?

There was no significant difference in the languages spoken or written between the study and control group. The number and type of languages used and written was dependent on the level of education that the parents reached.

iii) What are the main household sources of income?

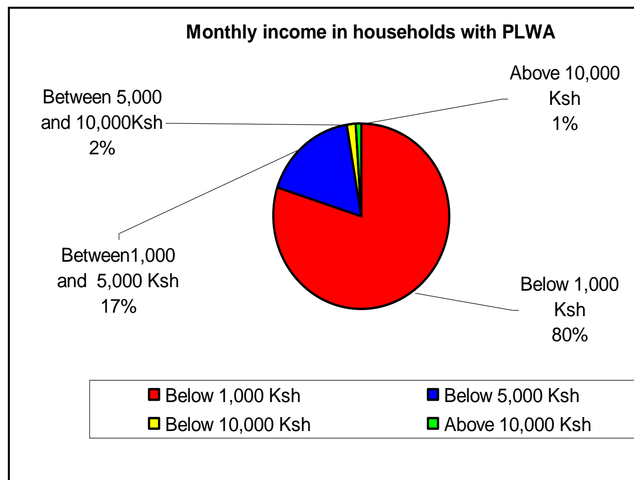
The most common source of income for both groups was farming. However, 21% more HH with PLWA relied on farming as their only source of income in comparison with HH with No HIV. In these HH, there were substantially more HH earning income from a salary or business suggesting that the majority of those HH where HIV/AIDS is present have to be reliant on small scale farming as their only income.

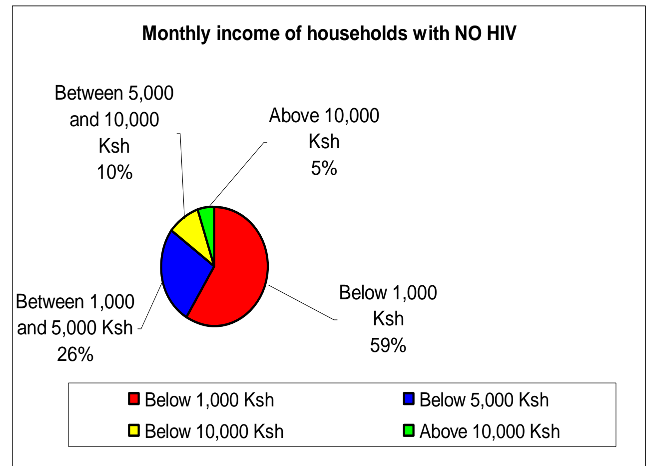




iv) What is the monthly income of households?

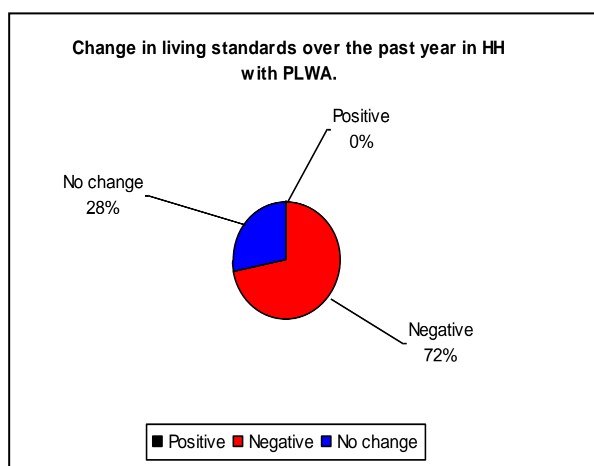
Predominantly the monthly income was below 1,000 KC a month. 41% of HH with NO HIV earn above this amount in comparison to 20% of those living in HH with PLWA.

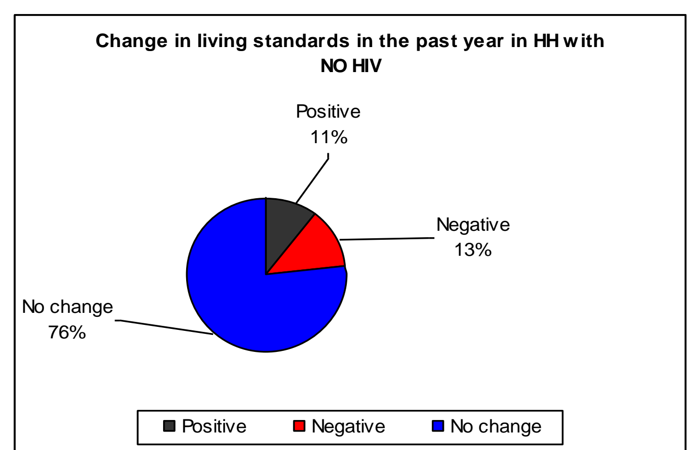




v) Have households experienced a change in living standards in the past year?

59% more HH with PLWA experienced a negative change in living standards in the past year, based on income.





vi) What is the HIV or death status of parents in HH with PLWA?

Whilst only 11% of children living in HH with No HIV had experienced the death of their father to different causes, 52% of children living in HH with PLWA had experienced the death of their father to HIV/AIDS. There was a greater prevalence of fathers dead in comparison to mothers. 22% of children in study households had experienced the death of their mothers to HIV/AIDS. However, the HIV infection rate in mothers was at 66% in comparison to 40% of fathers. With this high level of

infection, it is likely that those children who are paternal orphans will lose their mothers to HIV/AIDS in the near future. Only 2% of children in HH with No HIV had experienced the death of their mother to different causes. The 11- 15 years age range had experienced the most paternal and maternal deaths in HH with PLWA. Only 8% of fathers in HH with PLWA were not showing HIV/AIDS signs and symptoms and 12% of mothers.

vii) Who is the main carer of the child?

90% of children in HH with No HIV are cared for by their mother. The remaining 10% are cared for by a relation or neighbor, only 3% are cared for by their grandparents. In HH with PLWA, 21% of children are cared for by their grandparents and 8% by a sibling. Again in these HH, the main carer is predominantly the mother at 57% but the high level of HIV infection amongst mothers suggests that many of these children will be double orphans in the near future. The high incidence of grandparents taking care of children suggest that they or siblings will be the main carers for these children.

viii) Does the carer live in the Household?

2% of those caring for children in HH with PLWA did not live in the household.
1% of those caring for children in HH with NO HIV did not live in the household

B. Child information

The questions aimed to establish whether there were substantial differences between HH with PLWA and households with NO HIV in the following categories:

Health, Nutrition and Education

i) Basic health of the child at the time of study and in the past three months.
ii) Basic nutrition – number of meals and type
iii) Number of days in school
iv) Community assistance with food, clothing, shelter, spiritual guidance and counselling
v) Participation in clubs

Behaviour, Emotion and Social skills

vi) Experiences of anxiety, exhaustion or anger
vii) Experiences of bedwetting, nightmares, mood swings, hyper activity or withdrawal
viii) Exploitation, exclusion or discrimination from the community, family, school or friends
ix) Number of friends and hours they play
x) Life skills including the ability to clean oneself, awareness of safe sexual practices and inheritance rights and if they are given enough adult attention

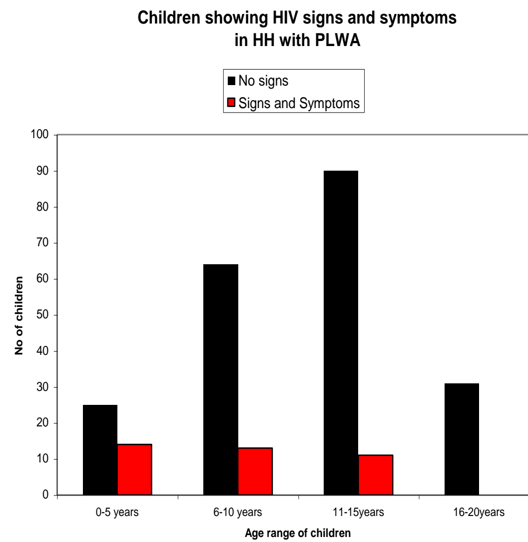
Manual Labour

xi) Number of children in labour
xii) Hours of labour
xiii) Payment

Health, Nutrition and Education

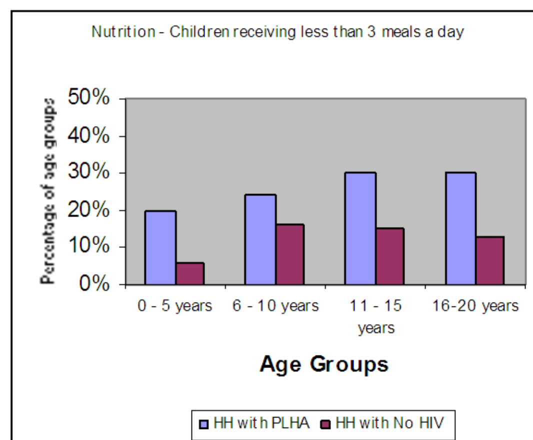
i) What is the basic health of children in both HH's at the time of the study and over the past three months?

There were significant differences in the health of children below the age of 5. 100% of children in HH with No HIV were healthy at the time of the study. 37% of children below the age of 5 in HH with PLWA were unhealthy at the time of the study and showing HIV signs and symptoms. Significantly, the older the age ranges the smaller the difference in health status. Children aged between 16-18 years in HH with PLWA showed no signs and symptoms.



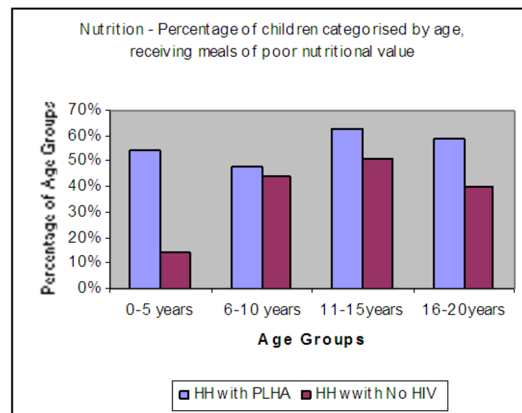
ii) Are there any significant differences in the number of meals children receive a day, depending on which type of HH they live in?

13% of all children living in HH with No HIV received less than 3 meals a day in comparison with 26% of all children living in HH with PLWA. The number of meals becomes more significant when the nutritional content is considered.



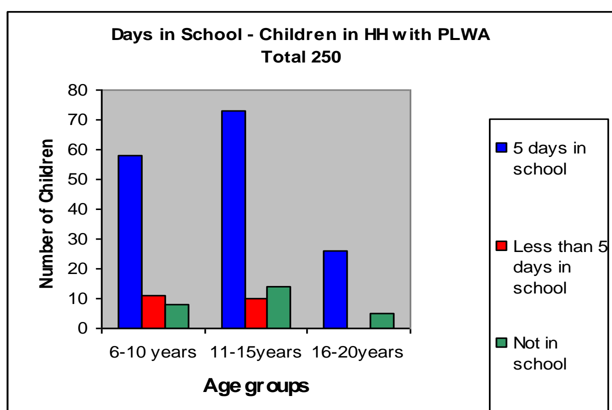
iii) What is the nutritional value of meals received?

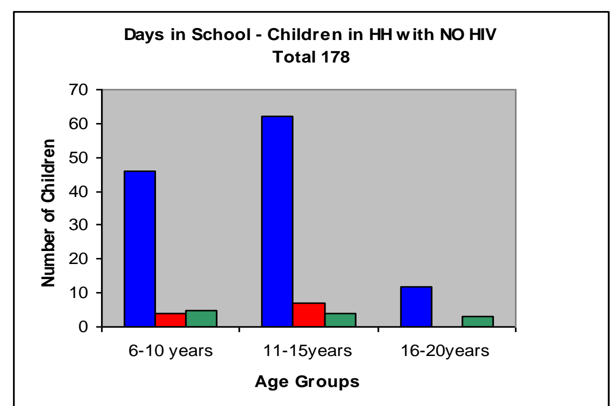
41% of all children living in HH with No HIV received meals that were of poor nutritional composition compared with 56% of all children living in HH with PLWA. The 11-15 year age range shows a greater prevalence of poorly balanced meals in both groups but it is significantly greater in HH with PLWA.



iv) Are the children attending school?

The majority of children of school going age, in both groups were attending. There were no significant differences in attendance or the number of days children were in school between the groups. 19% of children living in HH with PLWA were not in school in comparison with 13% of those children living in HH with No HIV. However, 24% of children aged between 11-15 years in HH with PLWA were out of school in comparison to 12% of the same age group in HH with No HIV. 80% of children aged between 16-18 years in HH with No HIV were in school; similarly 83% of children of this age range and living in HH with PLWA are in school. There were no significant gender differences in attendance either across study groups or age groups.





v) Do households receive assistance from the community with food, clothing, shelter, spiritual guidance or counselling?

6% of HH living with No HIV received help from relatives or friends for food and clothing.10% of HH living with PLWA received help from relatives or friends for food

and clothing. 63% of children living in HH with No HIV received spiritual guidance from the church in comparison to 67% of those living in HH with PLWA.

16% of children living in HH with PLWA received a form of counselling from one of the following grandmothers, teachers, the church and CHW. 10% of children living in HH with No HIV received counselling.

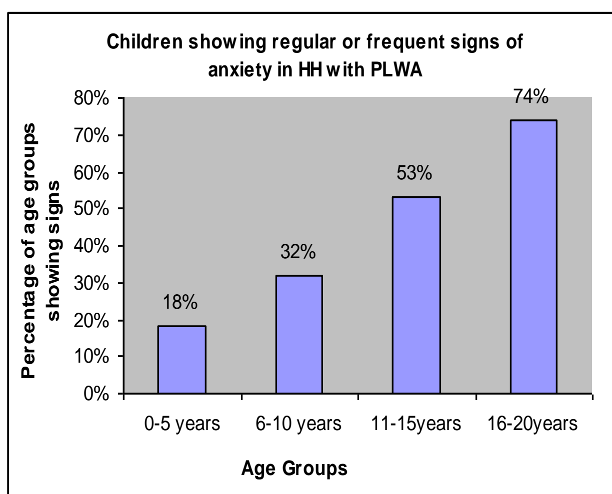
vi) Do children participate in clubs?

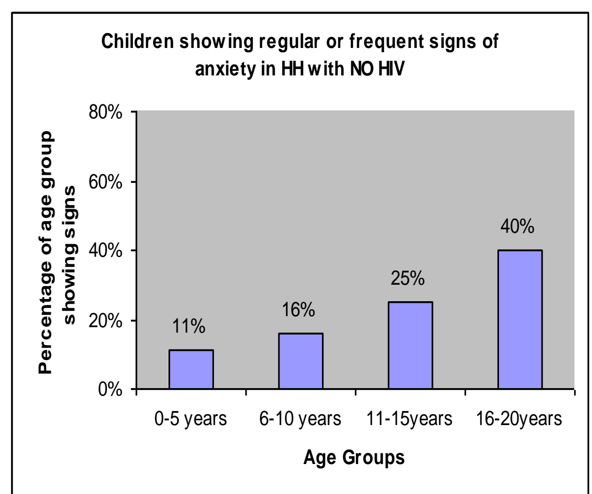
44% of children aged between 6 and 18 years, living in HH with PLWA, took part in school, sports or religious clubs. 48% of children aged between 6 and 18 years, living in HH with No HIV took part in school, sport or religious clubs.

Behaviour, Emotion and Social skills

vii) Do more children in HH with PLWA experience signs of anxiety more regularly than those living in HH with NO HIV?

There are substantial differences between the groups in the number of children experiencing frequent or regular signs of anxiety. This is particularly evident in the older age ranges, with a growth of 20 –35% more between the ages of 11 and 18 years.





viii) Do children in HH with HIV/AIDS experience more regular or frequent signs of anger in comparison to those living in HH with No HIV?

There was a small difference in the number of children experiencing regular or frequent signs of anger between the groups. In the 0-5 years, 6-10 years and 16-20 years range, between 13 and 15% of children in both HH exhibited regular or frequent signs of anger. There was an increase in the percentage of children aged between 11 and 15 years showing signs of anger. This age range showed that 25% of children in HH with No HIV experienced anger on a regular or frequent basis in comparison with 29% of those living in HH with PLWA.

ix) Do children in HH with PLWA experience poor motivation and exhaustion on a more regular or frequent basis than those living in HH with No HIV?

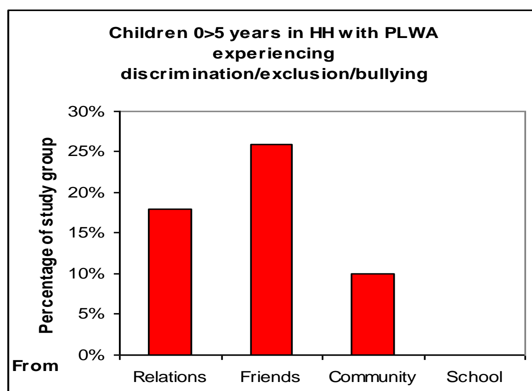
There is a marked increase in the number of children below the age of 5 living in HH with PLWA who experience exhaustion on a regular or frequent basis in comparison to those children in the same age range in HH with no HIV. This significant difference tends to lessen as the children become older, however the frequency of exhibiting poor motivation and exhaustion increases with age in both households. The number of children involved in manual labour must be considered as a contributing factor to this rise.

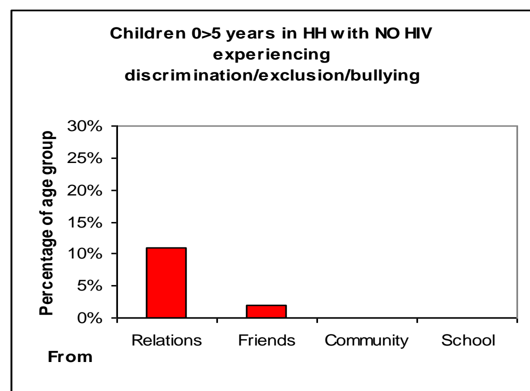
x) Do children in HH with PLWA experience any more significant signs of bedwetting, nightmares, mood swings, hyper activity or withdrawal than those living in HH with No HIV?

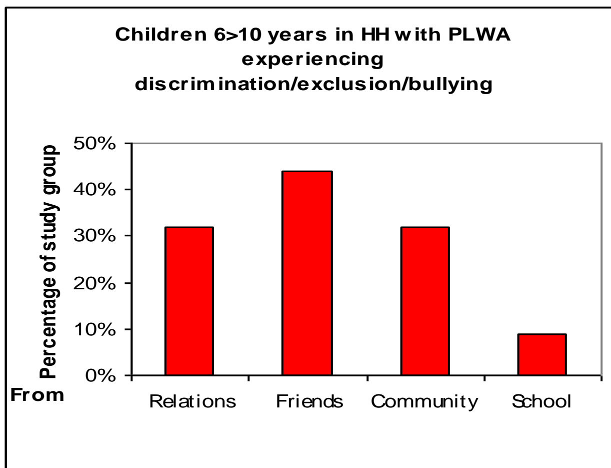
There were no significant differences between the number of children experiencing these symptoms in HH with PLWA and HH with no HIV. Experiences of bedwetting were commensurate with age

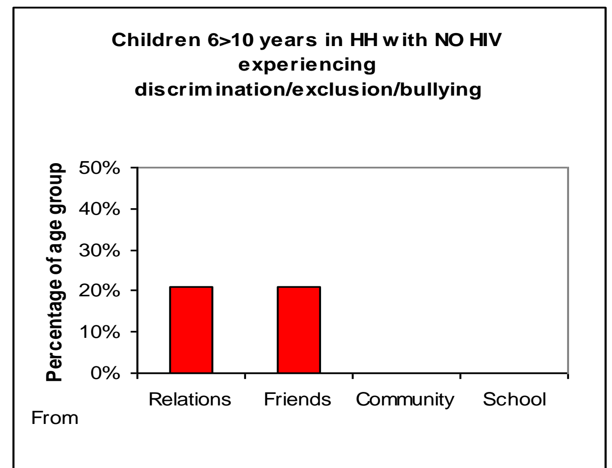
xi) Do children in HH with PLWA experience exclusion, bullying or discrimination from the community, family, school or friends on a more regular basis than those children living in HH with No HIV?

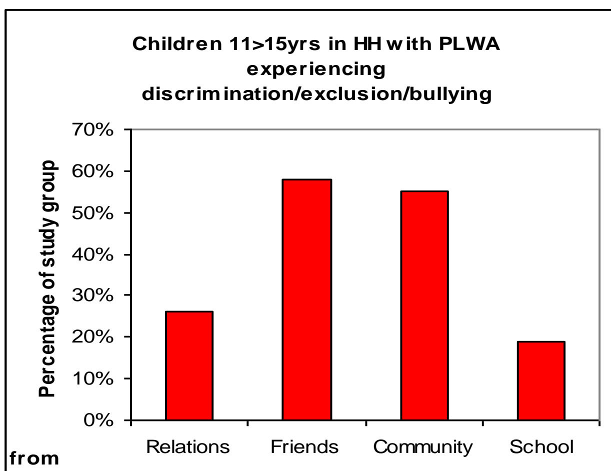
There were substantial differences in the amount of discrimination and exclusion that children in HH with PLWA were experiencing in comparison to those children living in HH with No HIV. This was particularly so in school and from the community.

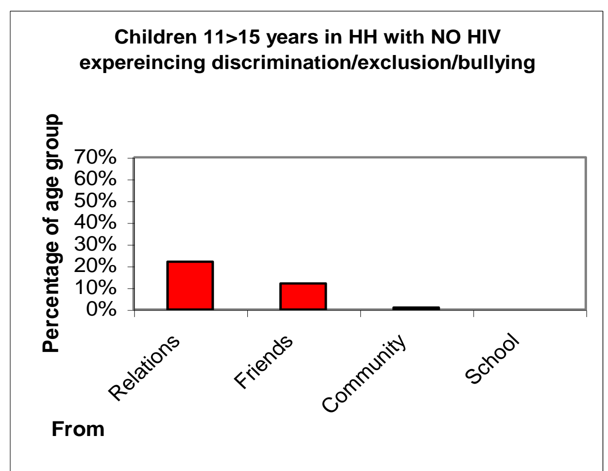


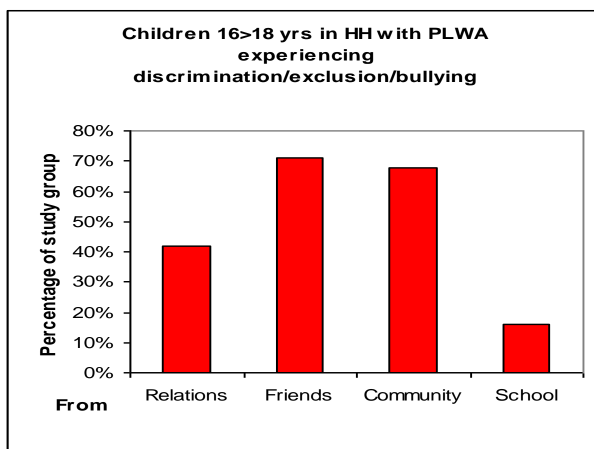


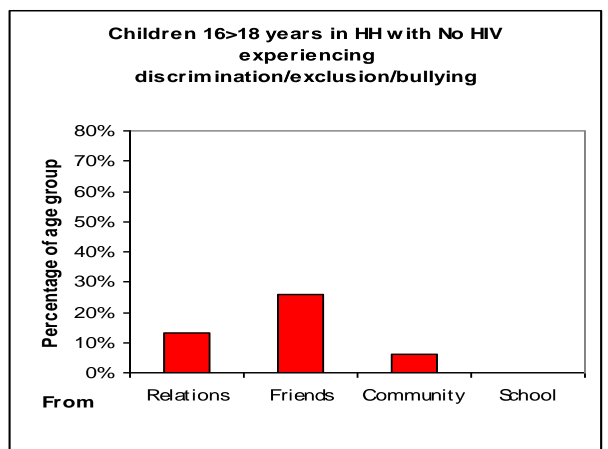












There are also a greater percentage of children in HH with PLWA experiencing discrimination from relatives and friends. This increase in discrimination increases with age, particularly from the years of 11 to 18. There were no significant gender differences. Whilst this discrimination is apparent, it is interesting to note that 10% of

HH with PLHA receive some form of support in the form of food or clothing from relatives or neighbours. This is an increase of 4% on the HH with No HIV.

ix) How many friends do children have and how many hours a week do they play with them?

There were no significant differences between the number of friends the children had and how many hours they played with them.

x) Are children able to clean themselves, aware of safe sexual practices and their inheritance rights and given enough adult attention?

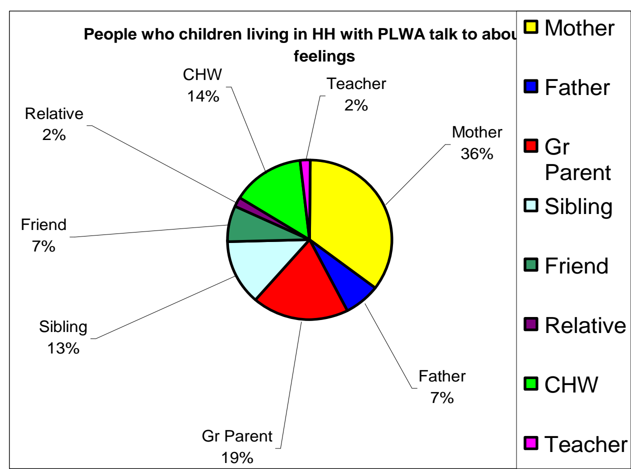
30% of children aged between 0-5 years living in HH with PLHA receive enough adult attention in comparison with 70% of those children living in HH with No HIV. There are 40% more children living in HH with PLHA who do not receive enough adult attention in comparison to those children living in HH with No HIV.

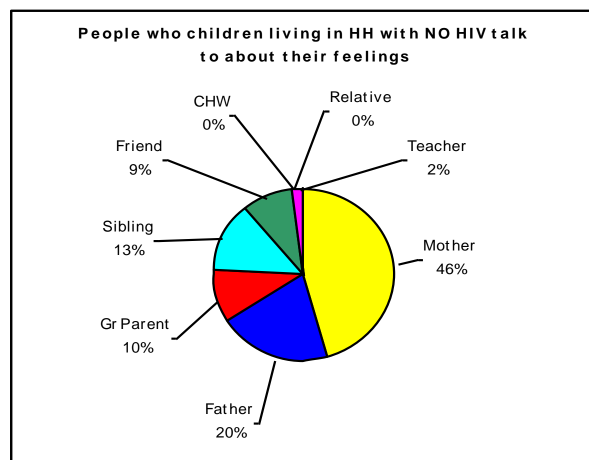
There were no significant differences between those children aged between 6-10 years living in HH with PLHA and those in HH with No HIV in any of the categories.

In the 11-15 year age range 50% of children in HH with PLHA were aware of safe sexual practices in comparison with only 10% of children in HH with No HIV suggesting that awareness has been raised due to the HIV disclosure of parents. 50% of both groups were aware of their inheritance rights.

There were no significant differences in any of the categories in the 16 –18 year age range. All children were able to clean themselves and 90% of both groups were aware of safe sexual practices and inheritance rights.

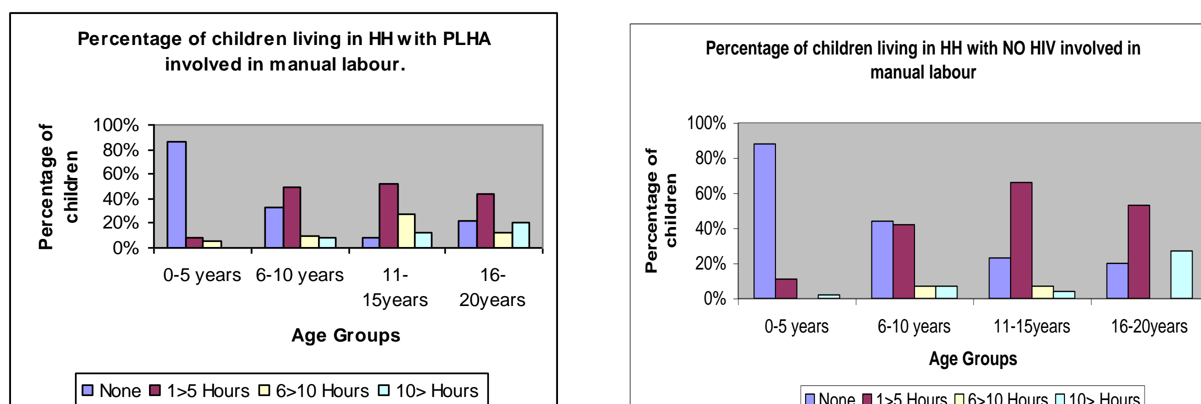
xiii) Who do children talk to about their feelings?





The mother is predominantly the person most children talk to about their feelings. However, in HH with PLHA where the death or sickness of the mother affects this role, both the grandparent and the CHW are taking on the responsibility. This indicates that the CHW is already taking on the role of counsellor in a number of households.

xiv) What percentage of the children are engaged in manual labour?



These findings show that between 40 and 60% of children between the ages of 6 and 18 years are involved in manual labour. There is little difference between the groups and the majority of children receive no payment for their labour.

Trainers of Trainers responses to questionnaires

24 ToT's completed questionnaires.

Elements of the HBC programme that need to be improved.

i) Provision of food for clients
ii) Improved drugs for clients including antibiotics and ART
iii) Improved provision of transport for CHW's
iv) Provision of transport for clients to hospitals
v) Increased training for CHW's
vi) More nursing equipment for CHW's
vii) More guidelines on VCT ie the provision of a manual
viii) More training in counselling skills on syndromic management of STD's and HIV/AIDS
ix) Social support

Problems to extending the HBC programme to meet the needs of AOVC:

i) Need for more training of CHW's
ii) Political interference
iii) The needs of all children in the community need to be met
iv) The number of AOVC will increase
v) Assistance might be abused by relatives
vi) Relatives will not take responsibility for their AOVC.
vii) Lack of financial and material support
viii) Lack of transport for effective operation
ix) Need for more long term funding for efficacy

x) Too much work for CHW's and ToT's

The differing issues that affect AOVC:

i) Lack of adult love and affection
ii) Lack of education
iii) Food
iv) Medical attention
v) Counselling and guidance
vi) Shelter
vii) Protection from exploitation
viii) Protection from HIV infection
ix) Lack the experience of normal childhood there is no peace in the house.

Training:

i) More training is needed in the form of seminars and refresher courses
ii) More training is needed in counselling and nursing skills
iii) As needs are diversified so there is a need for more comprehensive training covering all aspects of AOVC care.

Role of the CHW:

i) CHW's are unable to help PLWA with the needs of AOVC as they lack the funds and the knowledge of how to best address their needs.
ii) CHW's are able to address the needs of AOVC is their educational background is sufficient.
iii) Some CHW's so not have the literacy skills to undergo the necessary training.
iv) CHW's help guide the client how best to look after their children
v) CHW's need the support of ToT's to help them assess and address the needs of AOVC.
vi) CHW's need training in the psychosocial needs of AOVC.
vii) CHW's help to mobilise the community but need financing, training and transport if they are to address the needs of AOVC.

Existing community coping mechanisms:

i) Youth groups
ii) Church groups
iii) Women's Groups
iv) Community leaders
v) Many groups are ineffectual

vi) There are no active support mechanisms to help CHW's in their role

Ways to strengthen links to improve the nutritional, social, emotional and economic status of AOVC:

i) Network and develop awareness of existing groups operating in the area.
ii) Advocate legal support for AOVC from the government.
iii) Train support groups in the skills to accommodate the needs of AOVC.
iv) Create awareness and support for the AOVC programme within the community.
v) Increase funding sources.
vi) Develop communication between ICROSS staff, ToT's and CHW's.
vii) Develop inter-sectoral collaboration between Ministry of Agriculture, Ministry of Education, Ministry of Health, Churches, NGO's and CBO's.
viii) Implement community workshops for support groups, community leaders and PLWA and other members of the community to encourage local participation in the care of AOVC.
ix) Monitor the households of PLWA to assess their particular needs.
x) Create income generating schemes
xi) Mobilise the church to become more actively involved.

Responses from key informants - CHW's.

- What do you think should be improved upon in the HBC programme?

- Improve the morale of the CHW's.

-Provision of T shirts, uniforms, umbrellas or bags. (Other IMPACT organisations in Bungoma provide their volunteers with such items, which increases their status and encourages greater support.)

- Monetary renumeration.
- More bicycles for easier access to patients
- Bags for carrying medicine
- Improved and more drugs for the patients

- What does the community want and expect from you the CHW?

- Food particularly fruit

- Financial assistance for drugs
- More drugs
- Transport to and from hospital and health centres
- Assistance with the needs of their children
- Knowledge of who and where to go to for help for their children

• What in your view are the most important needs of AOVC's?
  - Food
  - Adult love and affection
  - Education
  - Income Generating Activities
  - Someone to talk to about their fears
  - Guidance in cleanliness, life skills and nutrition

• Do you feel that you are sufficiently trained to address the needs of affected children?
  - No

• What support programs for CHW's would you like to see in place?
  - More support from the local leaders
  - More communication between other NGO's and CBO's
  - Referral networks for AOVC
  - Financial assistance to help the families with PLWA
  - Activities that show appreciation for our work
  - More training of CHW's
  - More training in how to deal with the needs of AOVC

• What do you think the problems will be, to extending the HBC programme to accommodate the needs of AOVC?
  - Lack of time and knowledge on the needs of AOVC
  - Lack of financial resources
  - Lack of local resources, human and material
  - Community stigma and discrimination

- What is the best way to mobilise the community to address the nutritional, social and economic needs of AOVC?
  - Develop links between local leaders, schools and MOH
  - Train CHW's in nutrition
  - Advocate the work of ICROSS at funerals and barasas
  - Involve schools and local leaders in the HBC programme
  - Develop income generating schemes
  - Develop strategies to decrease stigma and discrimination
  - Involve the church in disseminating messages

Researcher's observations

Case studies of HBC clients in Bungoma district.

Christopher lives in the rural area of Bungoma district. It takes the CHW an hour by borda borda to reach his village and then a half an hour walk through the maize fields and sugar cane. Christopher lives in a one-room mud overlooking his small shamba. Christopher's house is deserted when we arrive and he is lying on matting outside his house, covered only by a blanket. He has no source of income except the small shamba that his wife tends, as he no longer has the energy to. Christopher is 50 but looks much older, he has seven children and many grandchildren. His family are attending the funeral of his one year old grandchild, hence why he is alone. Christopher struggles to sit up and only with the assistance of the CHW is able to. He is desperately weak, emaciated and covered in scurvy, rashes and open sores. The effort he has exerted to move prohibits him from speaking for a while. His breathing is laboured and he is sweating. Christopher has not eaten for three days. He has lost the appetite and the will. The CHW talks to him about his condition. Christopher has been in this state for a week now. He has lost all dignity, unashamed of his naked, waiflike body and unable to support himself. The CHW brings fruit and feeds Christopher mango piece by piece. Christopher says that often when he has an appetite there is no food. The CHW administers drugs, paracetamol for the pain and vitamins. He applies cream to his infections and rashes. Christopher is thankful for the company and the support. He says he feels better after the mango.

Violet lives with her five children and husband. She is the second wife of Johnston, the first died of HIV/AIDS last year. He has three other wives. Johnston is showing the signs and symptoms of HIV/AIDS and the CHW has been trying to persuade him

to go for VCT. He is reluctant. Violet has been ill for three years and is painfully thin. She sits on her bed, dressed and able to speak but her movement is limited and slow. When her husband is working in the shamba, their daughter Edith looks after her. She is thirteen. She is not at school and spends her day tending to her mother's wounds, bathing her and washing the sheets. She is also responsible for the cooking, cleaning of the house and looking after her siblings. The CHW sits and chats to the family about Violet's condition, giving advice and asking about her appetite. The CHW visits once a week and supplies cream for the rashes and itching and antibiotics for the open sores. Three weeks ago Violet was completely bedridden, her family thought she had passed away and had given up. The CHW administered vitamins and provided fruit. Violet is now able to move about the house and sit in the shamba. The CHW mentions that he has witnessed this extraordinary recovery many times with his patients. The administering of simple antibiotics, vitamins and fruit can prolong life many times over.

There are the funerals of two young children in the village today. The CHW has planned to visit four clients in the area. On hearing about the funerals he decides that we should attend them in order to advocate the works of ICROSS. The CHW recognises the funeral gathering as a forum for the dissemination of information and raising the profile of ICROSS. We arrive at the first funeral, having walked a further half an hour from the previous client. We formally introduce ourselves and pay our respects to the deceased and the grieving family. The CHW takes his turn to address the assembled community. He does not talk of HIV/AIDS but talks of opportunistic infections such as wasting, diarrhoea, skin rashes and sores. He also mentions other common diseases such as diabetes and malaria so as not to give cause for suspicion. He encourages the people to visit him if they feel they need help. He explains how ICROSS can assist with medical supplies and advice. When finished, we quietly take our leave and the forum continues. The CHW expects at least three potential clients to visit him after each funeral.

Words from HBC clients

'HBC has prolonged my life by years.'

'The family network can't cope with this disease. It is breaking down. We do not have the resources financially to withstand this. Our hearts are heavy, our bodies are broken and our communities are fragmented. We cannot cope with the children. We need help.'

Experience of a family with an HIV positive nephew:

Edgar is ten. He has been HIV positive since birth. His father died last year and his mother last week. Edgar has come to live with his aunt and uncle. Edgar has staved off the opportunistic infections but has in the last month started to develop abscesses and boils. His uncle took him to the District Hospital. He was told that there were no drugs available to give Edgar. If he required drugs he should go to HBC programme.

Observations from Project Manager, Field Officers and stakeholders

- The distances travelled by Field Officers are enormous. The area of a site can be up to 60km. An ICROSS field officer aims to visit at least one health centre a week and up to three clients a day. He/she can travel for two hours to visit a client, using matatus, borda borda or by foot. This travelling is rigorous and the task on arrival tough. With the use of a motorbike, their work could be doubled in a day. More CHW's could be monitored on their visits and more clients visited.
- Field Officers meet once a week to complete client profile forms and discuss issues in the field. There is a greater need for more regular meetings to monitor exactly what is going on in the field and where the field officers are on any particular day.
- Records need to be monitored, updated and evaluated more efficiently. Given that there is a need for accurate AOVC records, it is important that an effective system is put in place, one that is simple to update and to access. Workloads will undoubtedly increase with the extension of the programme to accommodate the needs of AOVC. Therefore it is necessary that specific roles are defined and regular meetings established before implementation.
- There is a greater need for communication between CHW's and field staff. Regular meetings need to be developed to incorporate issues that are causing difficulty in the field. Field Officers need to listen to the needs of CHW's and respond accordingly before discontentment breeds. Some decisions need to be made without having to consult the Project Manager for advice.
- CHW's are worried about AOVC. They become attached to the children and feel responsible for their welfare.
- CHW's have their own financial and social problems and this is an added burden.

- CHW's often use their own money for transportation of clients to the hospital or for VCT. They also provide fruit and are constantly asked to provide more drugs.
- CHW's and ToT's feel there is a need for the International Director of ICROSS to visit the programme.
- ToT's feel they should be released from some of their work duties in order to fulfil their roles.
- Before addressing the needs of AOVC it will be necessary to address the workload of ToT's and CHW's.
- There is a need for greater synergy between programme implementors.
- The recruitment of new CHW's requires careful selection, taking into consideration location, gender and literacy capabilities.
- Coping mechanisms for families of the deceased need to be strengthened and monitored.
- Observations through referencing recorded notes of past meetings and monthly and quarterly reports.

The following obstacles to HBC service provision were noted:

i) The trauma experienced by PLWA, their families and carers sets up a set of living standards that causes isolation from the community and at times a reluctance to participate in care. Social stigma is identified as an element to this isolation.

ii) Staffing on a volunteer basis has its difficulties as the economic status of participants is very low and the demands on them are high.

iii) Supplies and materials are often in shortage.

iv) The geographical area requiring service is large and difficult to traverse by the currently available means.

v) Volunteer workers are affected by the psychological burdens of depression and burnout whilst undertaking their tasks.

vi) Miscommunication and misunderstanding as to the role of HBC and how it serves the community are a factor to the running of the programme. The notion of volunteers and reimbursement represent a growing problem and this needs to be clarified at all levels of the programme.

vii) Record keeping and the transferral of information such as client health records require special attention as language and cultural barriers hamper the upkeep of accurate data.

viii) The current reach of the programme is well below target and reasons for this need to be addressed before the programme can be extended to accommodate the needs of AOVC.

ix) The recruitment of CHW's with varying educational and social backgrounds complicates the issues of training and taking on further responsibility. Whilst those with little or no literacy are often the CHW's who serve the most clients most effectively, they are at the same time limited in their ability to take on more responsibility and more complex training.

x) Lack of incentives for CHW's and limited financial resources could be having a detrimental effect on the number of clients they are recruiting.

Conclusions

Through a thorough analysis of the findings, and a comparison with current literature about ways in which communities are coping with the HIV/AIDS crisis, the following conclusions have been made about:

i) Existing community perceptions of the HBC programme

ii) Existing coping mechanisms

iii) The needs and circumstances of AOVC

It has been necessary to identify the strengths and weaknesses of the existing programme and to identify existing community coping mechanisms so as to guide programming.

i) Existing community perceptions of the HBC programme:

- The HBC programme has had a positive impact on those PLWA in the community. Lives have been prolonged; positive living and improved living standards have been enhanced.

- The HBC programme has highlighted the issue of AOVC and the need to extend the programme to address their needs.

- The HBC programme has had a positive impact on the number of PLWA admitted to hospital. Care by CHW's in the homes of PLWA has reduced the number of patients needing care in hospitals.

Expectations:

The following issues are those that the community feel are the most pressing and should be accommodated within the HBC programme:

- Provision of food to PLWA
- Increased provision and improved quality of drugs
- The training of more CHW's in HBC, nutritional awareness and the psychosocial needs of AOVC. As the majority of those already trained are women, there is a need to train more men in the hope that it will encourage more clients to come forward and will reduce stigma and discrimination. Other members of the community to be trained are community leaders and youth.
- More regular visits from CHW's
- Increase incentives for CHW's so as to improve morale and performance
- Improve transport facilities to and from hospitals and health centres for PLWA
- Advocate for the wavering of medical fees and VCT expenses
- Responsibility for the welfare of AOVC

ii) Existing community coping mechanisms:

- It is evident that there is a discrepancy between the number of existing support systems, their efficacy in reaching PLWA and community awareness of their existence. It is apparent that PLWA, community leaders and the community at large are unaware of the systems that are available to them and their rights to the use of such services. There are a substantial number of NGO's, CBO's and women's groups operating in the area of HBC and the IMPACT partners play an active role in the support of families living with HIV/AIDS. However it is clear, that particularly in the rural areas, they work in isolation and in many cases are unaware of each other's existence or focus. There is a need to generate a greater awareness at the grassroots level, of the social services and support mechanisms available to the community. The effectiveness and working ethic of these groups needs to be closely scrutinised in order to maximise their potential impact. There is a need for closer collaboration between existing groups, MOH, community leaders, churches, schools, CHW's and PLWA so as to develop community based referral networks and utilise all the locally available resources.

- The CHW's at present are lacking incentive and positive morale. The influence of monetary rewards for volunteers from other organisations working in the area has led to a volunteerism based on financial reward and competition. ICROSS

believes that to develop a sense of sustainable and workable community responsibility there must be no monetary incentives. The initial essence of the HBC programme and the voluntary basis of the CHW's is disintegrating as NGO's in the area are perceived to be affluent and volunteers look for rewards that do not exist. This leads to a change in the basic ethos of the organisation and in turn is reflected in the calibre of those who volunteer for HBC training. This is also reflected in the community's perception of how they think that ICROSS can help, namely in the provision of food, drugs and school fees.

- The level of poverty and the extent to which HIV/AIDS is impacting the economic, social and human resources in the area, means that extended family networks and community coping mechanisms as they exist, cannot withstand the demands that are being placed on them. There is a need for the restructuring and efficient co-ordination of existing coping mechanisms so as to develop an effective, sustainable and regular service.

- Entry stage into the HBC programme is late, resulting in the treatment of clients who are terminally ill, with a low quality of life and a life expectancy of 6 months to one year. Research indicates that if HIV infection is recognised at an early stage, interventions can maintain a client's health for anything between 5-10 years, at a stage when the quality of life is relatively normal. If HIV/AIDS is diagnosed early, it can be managed as part of the HBC programme as a chronic disease rather than a terminal illness. VCT needs to be encouraged before the onset of full blown AIDS. With early intervention, positive living and the quality of life can be enhanced thereby encouraging more clients to be tested early as the benefits of the HBC programme are witnessed.

- Support systems in nutritional awareness are lacking in the area. PLWA are lacking information and knowledge of the medical, physical and emotional benefits of a balanced diet and this needs to be more widely disseminated. Advocating for early VCT, combined with nutritional education will enhance and prolong lives.

- Existing support systems are attempting to address the stigma and discrimination that is associated with HIV/AIDS but there is a need to confront it more openly from the National level down to the community level. This involves greater collaboration and communication between the MOH, church, schools,

community leaders and the community at large. Influential church denominations in the area that work against the fight against HIV/AIDS should be made accountable and efforts to abolish them encouraged.

iii) The needs and circumstances of AOVC

- There is a need to establish a reliable record of the total number of AOVC and their needs, specifically monitoring those caring for PLWA. The upkeep of this record needs to be administered by a diverse representation of the community at a localised level.

- Community responses suggest that one of the main priorities for children of PLWA is assistance with school fees. The percentage of children living in HH with PLWA who are attending school is surprisingly high which indicates that families are finding ways, however difficult, of educating their children. The community's perception that ICROSS can help with school fees is misguided and it needs to be clarified exactly what role ICROSS can play in the recovery process. The issue of financial assistance for schooling needs to be addressed at the national level in collaboration with CACC's and local leaders. Schools, however, do have a role to play in the monitoring of AOVC in collaboration with local churches, community leaders and NGO's. HIV/AIDS awareness and education in schools needs to be monitored and evaluated efficiently to ascertain how and if, the national HIV/AIDS curriculum (KIE Curriculum) is being implemented and the degree to which it can be extended to accommodate the psychosocial needs of AOVC.

- Children living in HH with PLWA show a greater regularity of receiving meals of poor nutritional content than those in HH with No HIV. The nutritional value of meals in all households is significantly low and suggests that there is an overall lack of awareness of a healthy diet, which is only compounded by poverty. The geographical area is agriculturally rich but the abundance of crops does not reach the majority of people, suggesting that there are the resources but not the infrastructure to accommodate the high demand. Existing agricultural CBO's need to be mobilised to address this issue.

- There is a greater need for children in HH with PLWA to be trained in income generating schemes without compromising their education. The psychological and material benefits of self-reliance, self-efficacy and self-esteem are

innumerable and the local resources, material, educational, social and organisational, need to be utilised more effectively.

- Children living in HH with PLWA experience discrimination and stigma more frequently than those living in HH with No HIV do. This is particularly so from the community and school. Ways to reduce stigma need to be addressed in a culturally sensitive way that involve the whole community. Children living in HH with PLWA display more frequent signs of anxiety, stress, exhaustion and poor motivation whilst receiving less adult attention. Different children exhibit different behaviours which, coupled with a lack of adult affection and love manifest themselves as symptomatic of psychological distress. There is a need to address these issues sooner rather than later, to prohibit childhood delinquency and promote self-sufficiency and the sustainability of community recovery.

- There is a need to strengthen adult awareness of the rights of all children particularly AOVC, as stated in the Convention of the Rights of the Child in the context of HIV/AIDS (UNICEF1999.) Existing schemes and programmes need to be utilised and developed in order to increase community members' responsibility in the safeguarding of those rights. Community's perceptions of the role of the child must start to marry with the changing roles that children are undertaking due to HIV/AIDS.

Recommendations:

- In view of the negative perceptions of some of CHW's, ToT's and PLWA about the HBC programme, there is a need to challenge these through engagement in discussions. The role of the community in the programme and the underlying ethos of the organisation needs to be clarified in order for efforts to be sustainable and effective.

- There is a need to advocate at the local and national level for the wavering of medical and VCT fees for PLWA and encourage testing before opportunistic infections take hold. This early testing and the implementation of nutritional interventions will help to prolong life at a relatively normal level of health. This in turn will enable the HBC programme to manage HIV/AIDS as a chronic disease as opposed to a terminal illness.

- Improve morale of the CHW's and ToT's by arranging quarterly meetings, which include lunch and a token of appreciation for the work that they do.

- Ensure that CHW's, ToT's and Field Officers are involved in, and aware of all activities and encourage greater communication between sites. Through greater interaction with Head Office and other HBC programmes it is hoped that the perceptions of management are demystified and lessons are learnt from each other.

- Improve transport facilities for Project staff by providing motorbikes or a vehicle to help cover the large distances and to improve access to health facilities.

- Sensitise community leaders about the HBC programme and the needs of AOVC in order to advocate for their involvement in the programme.

- Mobilise the community about the needs of AOVC.

- Recruit and train more CHW's in HBC. The majority of existing CHW's are women and there is a need to recruit both women and men for training. It is hoped that in the long term there will be both a gender balance and a status balance of trained CHW's. It is hoped that the recruitment of community leaders will widen the reach and reduce the stigma and discrimination that is associated with HIV/AIDS. The recruitment of youth, will develop HIV education and awareness and enhance sustainability. By developing a system in which CHW's are categorised, their roles can be easily defined according to attitude, literacy skills and geographical location, thereby creating a network of support with different levels of responsibility.

- Adapt and develop a manual of training to train existing and new CHW's in the psychosocial care of AOVC, the nutritional needs of the community and ways in which to recognise vulnerable children.

- Establish AOVC committees at the sub location level, recruiting community leaders, church and school representatives, PLWA, CHW's, ToT's, MOH. Monthly meetings to be held. Advocate for the appointment of community level CACC representatives to be part of the committee.

- Advocate for the local government to decentralise responsibility for AOVC and use existing land / building such as a Health Centre or advocate for land to be donated so as to establish a community focal point at the sub location level. This centre will act as a referral point for all NGO's, CBO;'s, MOH, schools, churches and community leaders to address the needs of the whole community, including PLWA and AOVC. It will also act as:

i. A place to mobilise the community to take responsibility for AOVC.
ii. A catalyst for greater communication between stakeholders and will therefore increase awareness of the support systems that are available to the community.
iii. A central point to implement income generating schemes, village banking schemes, food and finance sharing schemes, and workshops to improve self efficacy, educate about land and inheritance rights, life skills and agricultural and nutritional awareness.
iv. A centre for counselling for AOVC and PLWA.
v. A place where the needs of AOVC can be monitored and evaluated.
vi. Potential VCT centre.
vii. A place where PLWA can meet regularly to talk and gain support from each other.
viii. A central place for all the community. By involving all members of the community in activities stigma and discrimination will be reduced.

Responses from dissemination of the findings

Dissemination was conducted in the three sites and involved CHW's. ToT's, Women's Groups, Community Leaders, PLWA, CBO's, NGO's, Steering Committee and the MOH.

The following issues were noted:

School fees are still a problem - despite fees being free, the expenses such as uniforms, books etc are proving too much for parents and children are attending school without the equipment to benefit effective schooling. Participants requested that ICROSS advocate for the wavering of the additional costs of schooling for those children who are particularly vulnerable. Through AOVC committees, children's needs can be effectively monitored.

- Participants mentioned the methods of recruiting more CHW's as potentially problematic. The more literate the CHW, the more demanding the volunteer and the likelihood of incitement of other CHW's in the request for monetary rewards. Some NGO's hand out rewards regularly and this creates an expectation amongst volunteers, which in turn affects the type of people volunteering for training. The recruitment of the right sort of volunteers needs to be addressed. Community Leaders were perceived to be the hardest people to recruit without monetary reward. Their expectations are rather high i.e. expecting transport, lunch and sitting allowance. There is a need to educate the community leaders about the need for a change in attitude towards volunteerism so that the community can start to recognise the benefits of their taking responsibility for AOVC without expecting remuneration. CACC members were mentioned as adding to the problem by paying themselves heftily and not really considering the repercussions of their actions. The recruitment of men was seen as problematic as they are less willing to volunteer in comparison to women. The use of Church, Self help, Youth and Women's groups as a forum for mobilising volunteers would help to encourage more men to come forward. Awareness of the programme needs to be more widely disseminated, particularly amongst the men of the community.

- The development of Income Generating activities for CHW's would help improve incentive and add to community resource building.
- The focal point should be acquired through community effort. The notion that the HBC programme might donate funds to establish a building are misguided. The extension and use of an existing building as a referral and information point would be the most effective use of resources.

Recommendations for further research

Given that a significant number of children in HH with PLWA are exhibiting signs of the psychological symptoms of trauma and distress, there is a need for further in-depth research into the psychological impact of HIV/AIDS on AOVC. Implementation of the Achenbach Children's Behavioural Study is recommended as a short-term study, alongside a long-term psychological surveillance.

The findings suggest that, the nutritional intake of a substantial percentage of households in the study area is significantly below the recommended balanced diet. The Kenyan District Population Projection for 1995 –2000 states that the nutritional levels of children in the Bungoma area are low in relation to some other parts of the

country. The proportion of children who are stunted in the area is 41% compared to 35% nationally and those children considered wasted, when measured weight for age, resulted in 35% of the under fives. Given that protein and iron deficiency are considered the most prevalent nutritional disorders in the district, there is a need for research into the nutritional status of children and PLWA. This research would help guide programming for nutritional education and the long term sustainable benefits, nutritional interventions in the enhancement of health for PLWA in the HBC programme and in the implementation of income generating schemes.

In order to adapt nutritional education programmes to the specific area, there is a need to assess the existing local agricultural schemes, the production of horticultural crops, cash crops and oil crops and look at ways to utilise their potential to improve the nutrition, health and economic capacity of communities in the area. The proliferation of crops for part of the year suggests that the Bungoma district has the potential to develop support mechanisms that are effective the whole year round.

Given that the monthly income of the majority of those living in the study area is below 1,000 Ksh per month and that parents are still managing to send their children to school, research on the economic and social survival skills in the area would be beneficial. This would give a better understanding of the ways in which households prioritise their spending and the kinds of strategies that are being adopted as coping mechanisms.

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