

**THE CHALLENGES OF HOME BASED CARE FOR AIDS
PATIENTS IN ETHIOPIA**

by

BERHANU DEMEKE MD.

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Berhanu Demeke, MD

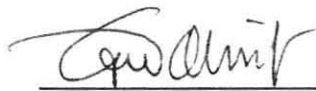
Department of Community Health
Faculty of Medicine, Addis Ababa University

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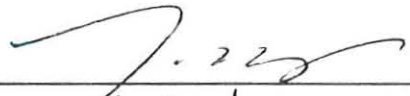
Dr. Derege Kebede
Chairman, Department
Graduate Committee



Dr. George Olwit
Advisor



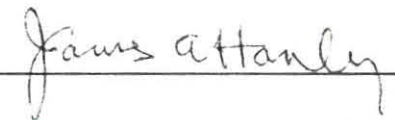
Dr. Tesfaye Shiferaw
Examiner



Dr. Pierre Duplessis
Examiner



Dr. James Hanley
Examiner



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ABSTRACT

This is a descriptive cross sectional study to determine factors which can influence and pose challenges for Home Based Care for AIDS Patients . The setting was Entoto Awraja , North of Addis Ababa , Ethiopia .

Four hundred eighty five persons from the community members of Entoto Awraja ; 37 AIDS patients attending counselling and follow up clinic ; and 12 family members who were informed about their patients disease , were interviewed by structured questionnaires, while 127 health institution workers involved in the care of AIDS patients in different health institutions were given self administered questionnaires .

The communitys', patients , families and health institution workers , Knowledge , attitude , beliefs and practices on AIDS , hospital care and home based care of patients was assessed . More than 60% of respondents had good knowledge about transmission routes and means of preventions , although 70% of them mentioned nonspecific symptoms of the disease . 61% and 81% of the community and health institution workers respectively did not think the hospital would meet all the needs of AIDS patients , and 57% of the community preferred Home Care compared to 40% of the patients , 25% of the family members and 43% of health institution workers. Majority of the patients and families were afraid of social consequences by being exposed due to visits by home care team. 60% of the community responded they will be volunteers for home care team , if asked while only 35% of the health institution workers responded similarly .

The study reveals considerably good knowledge

among the respondents on AIDS ,with bias towards clinical care and lees emphasis on th psychological support . The community displays less fear for AIDS and more positive attitude towards home care than health intitution workers.

Promotional and educational efforts are recommended , with emphasis on health workers for the success of Home Based Care.

I INTRODUCTION

Historically, medical care, is known for giving preventive measures, ameliorating stressful conditions or curing illnesses. There are well established primary, secondary or tertiary medical services for many illnesses. But AIDS has been continuously a new challenge. Many of the solutions which are mostly temporary, need ways and means, beyond the traditional medical approaches. Although many trials have been done by different scientists throughout the world, up to now, no effective preventive or curative means has been able to be produced. The fact that , AIDS is a social , political, and , economic problem, affecting all socio-economic group makes the situation difficult to deal with .

According to the WHO. Global programme on AIDS by early 1992 an estimated 9 to 11 million adult men and women worldwide were already infected with HIV (1). Worldwide the number of adults and children who have already developed AIDS disease is estimated at about 20 million. WHO predicts that by the years 2000 a total of 30-40 million men and women and children will to have been infected with the HIV. By the end of the 1990, there will be over one million adult AIDS cases. In this report it was estimated that 64% of these will be present in Sub-Sahara Africa . In Africa one out of three

sexually active adults in urban areas and 1 out of 5 to 6 in rural areas are HIV positive (1).

Ethiopia was considered to be of low HIV prevalence up to 1988. But subsequent surveys have revealed annual rates more than 60% up to 100% in vulnerable groups. In the general population the infection rate was seen to double every 2-4 years (2). By May 1993 about 500,000 people are estimated to be HIV positive. Up to November 1992, there were 3,978 cases reported by the Ministry of Health, Department of AIDS control (3). According to estimates of the MOH Department of AIDS control in 1994 there will be 18,315 new adult cases and 7,578 new paediatric cases. The number of new cases/year is expected to increase by a factor of 7 up to 1996 (4).

The rapid increase of cases has resulted in increasing prevalence of related diseases such as tuberculosis, which has led to overcrowding of already limited number of health facilities. In some parts of Africa 80% of hospital beds are being used for treating AIDS patients (1). In Ethiopia 30% to 40% of beds are being occupied by AIDS patients (4). As estimates from Department of AIDS Control show, up to 1996, the number of new cases will increase 31,000 per year, for adults and 13,400 per year for paediatric cases. In the country, figures show that there are 11,500 beds (4). Although

all new AIDS cases may not require hospitalisation, it is clear that there will undoubtedly be a great burden on hospital beds .

The treatment cost at present time is increasing to a very high level . This has caused economic inaccessibility for many patients . According to a study done in Addis Abeba and rural central Ethiopia in 1987 , the mean treatment cost for modern care was found to be as high as 45 Birr in comparison to the cost of self care , which was reported to be on average 6 Birr(5) . In the same study 30% of the patients who did not seek any medical advice were from low socio-economic group . Although this report is for any type of illness it is assumed to increase for AIDS cases . A hospital survey done in USA in 1987 revealed that almost one quarter of all AIDS patients , had no form of insurance and only 5% of the nations hospitals treat 50 % of the the patients (1). In another study it was estimated that overall cost of AIDS patients over a life time was estimated to be 147,000 US\$ per cases .

Therefore, the fact that AIDS is a complex problem having social , political, and economic impact on all socio-economic status, the rapid increase of cases , getting us from HIV to AIDS pandemic , the overburden of health institutions due to rapid increase of cases and high prevalence of related diseases , the high cost of

treatment , causing economic inaccessibility for most patients , calls for more feasible and sound management scheme which possible to solve these interlinked problems of this challenging disease .

In Africa, traditionally it is known that the family is the greatest source of strength to patients . Caring for patients usually involves the whole of the extended family . In many studies it has been shown that self-care constitute 40% to 50% of all care. In a study done by Yayeherad K. in 1987, 30% of the patients resorted to self-care . The reasons for using self-care according to this study were mainly , underating the disease as minor (40%-60%) and poverty [10%-39%] (6).

Because AIDS is such a threat to individuals and the community as a whole it requires designing of effective strategies which helps to combat the problem in its totality . One of such strategies is designing a programme which can help to see in to different aspects of problems of AIDS patients and thier families , and therefore of the community itself . Home Based Care programme is recommended because it is considered to be the way to solve the already mentioned complex problems of AIDS .

II LITERATURE REVIEW

It is observed in many instances that the outlook about AIDS is that of distortion, and prejudice. Due to partial understanding or total misunderstanding by individuals, families, groups or community as a whole the reactions are mostly that of fear. This has resulted, in becoming a barrier, for initiations of responsible collective actions to confront the epidemic. Rather, most of the reaction emphasise on blame and accusations that have helped the disease to hide more in the society and continue on spreading. A more positive response in the future has become the central goal when fighting against AIDS.

Public Health workers understand very well that "Health Promotion" means "the process of enabling individuals and communities to increase control over the determinants of health and thereby improve their health", (8) . This is why the role of communities are promoted in 1992 world AIDS day message. The WHO has declared World AIDS, Day Dec. 1st, 1992 to be emphasized on the role of communities responding to the requirements of HIV/AIDS pandemic(5). Communities are very important not only for provision of care and support but also for playing major role in prevention. In times of crises

such as AIDS, people affected by it will feel sense of worthlessness, insecurity, and sense of losing their identity. Strong social support network are very valuable at this times, to assist these people, by sharing feelings, giving encouragements & share information . When the community is seen as caring, and responsible, the patients and families will be more open, patients will not feel resentment and become careful on spreading the disease. But if the community is not caring the resentment felt may even to taking revenge and spread the disease recklessly.

The problems of AIDS patients have been described to be complex, multiple as well as interlinked. This calls for Home Based programme which will provide service appropriate to the patients complex needs.

Home Care is the type of care that takes place in the home and the service provided by the programmes through home visits. The main aim is strengthening and giving support to patients and families. It increases the role of the families caring for the patient by facilitating support through provision of resources. Although such programmes are operating in some African countries like Uganda and Zambia since 1987 (G.C.) similar ones were started earlier in the U.S. as well as Europe.(10,11,12). In Ethiopia such programme has just started through the chairmanship of Department of AIDS

control (DAC) by ten non-governmental organizations which are mostly religious. The organization formed is called Organization for Social Services for AIDS (OSSA). Although OSSA was formed since 1987, it was not functional up to know (4).

When home based programmes are recommended to be the best solutions for the multiple demands of AIDS patients and families one need to look into these demands, closely (10,11,12,13).

1. psychological -As AIDS is characterised by lots of stigma such as isolation, rejection, and fear, since it is a terminal illness people need psychological support to carry on for the remaining of their lives. Psychological support will also help to prevent feeling of hopelessness and high rate of suicide present among the patients resulting from frustration and anger upon medical service. Many pregnant AIDS/HIV positive women will have the psychological trauma of carrying on the pregnancy up to birth. There is also the necessity to change sexual behaviours which can affect sexual intimacy and therefore causes despair and anxiety. For all these problems patients requires tremendous amount of help.

2. Social Support -This mainly entails physical help such as moving them in bed, fetching water, doing bed, washing clothes, accompany them to clinics etc. It also includes the prevention of isolation, rejection and hatred which

patients experience.

3. Economical support - Although AIDS does not discriminate between race, colours, social or educational status, as well as economic status, when it happens to the economically underprivileged, the effect is even more. Therefore patients and families will be in need of money, clothing, adequate and nutritious food for the patient or even housing if they are forced to leave a rented house. If the patient is the breadwinner the whole family suffers of economical deprivation .

4. Spiritual needs:-It is a well known fact that faith, beliefs and tradition affect an individuals'life. This is very true especially in Ethiopian society . Therefore spiritual support will give to many patients with terminal illness like AIDS, comfort, and moral strength, with hope so that they can cope better with feelings of guilt, fear, anxiety, anger, or confusion.

5. Health Care:-Most common physical complaints of AIDS patients after the critical days during admission have passed, are minor ones. These complaints can be managed at home by taking appropriate medications during visits by the home care team.

Therefore in order to meet the above mentioned demands of the patients the objectives of Home Based Care programmes are:

1. To visit people with AIDS/HIV in their home in

order to assess their psychological, social, economical, spiritual and health care needs.

2. Give appropriate care and support for the patients as well as families, according to their needs.
3. Carry out counselling activities to patients, families, and give health education to the community to promote attitude and behavioural changes.

Considering the trend by which the number of AIDS cases is increasing it is evident that let alone for hospital care, number of patients has to be done carefully with the consideration of multiple factors such as, clinical condition of the patient , social , economic, and demographic characters of the patients .

Reasons for Home Based Care

Home based support is the key to decentralizing AIDS Care. It has significant role in easing the burden of overcrowding in hospitals . It is also a well known fact that family is the greatest source of strength to patients. Due to Home Care, isolation of patients from families and the community is prevented. The programme also helps to have extensive promotional activities through educating the community. The care is generally believed to increase quality of life for the patients them hospital care.

Home Based Care has the benefit over hospital care that it is more convenient and more personal, and is less costly . More people are served due to its wider coverage. The programme ensures equity, accessibility and it emphasis on prevention, community involvement, decentralization and integration. It gives the community the ability to self care and self empowerment.

Previous expreiences in Home Based Care

Eventhough OSSA has been organized but remained non functional we can refer to experiences of other Home Care Programmes which are present in Uganda and Zambia.

According to a review report by WHO Global programme on AIDS, the six home care programmes reviewed were:(10)

1. Chikankata Home Care and Prevention Programme - Mazabuk Zambia
2. University Teaching Hospital - Home Care Project (UTH)-Lusaka, Zambia
3. The AIDS Service Organization (TASO) - Kampala-Uganda
4. Nsambya Mobile Home Care Team (NSA) - Kampala Uganda
5. Kitou Mobile AIDS Home Care and Education Programme and pastoral Care and counselling programme (K,T) Kitouu, Uganda

6. TASO (The AIDS service Organization (TASOM)
Masaka, Uganda

It was mentioned in the review that, 4 out of 6 programmes are hospital initiated and hospital based while two are community based. The reasons for starting the programmes includes: ensuring future bed capacity for patients with diseases other than AIDS and people's preference to pass their terminal days at home, choosing home care as an alternative to hospital care. Most of the programmes gave Home care in combination with counselling and education.

All the programs offer home care to those who are affected by HIV/AIDS only. All the programmes considers AIDS as medical, social psychological and economical problem. In some spiritual supports were also included. In some of the programmes the team was composed of clinical officers, medical assistants, nurses/midwives while in others there were no clinical officers and clinical diagnoses was done by the nurses and midwives alone. Most patients are referred from hospitals but three of the programmes accepts also self referred patients.

As mentioned in the report the experience of all the programmes was very encouraging. There was no decline of patients from the programme, although sometimes, fear of and stigma attached to the disease has caused some

families to be frightened and refuse to care to sick family member. Among the six programmes only one of them does contact tracing in collaboration with patients as part of home visits. All of the programmes follow patients until death. All services and supplies in all the six programmes are provided free of charge except for fees of hospital care in two of the hospital based programmes. Community participation in the implementation of the programme varies where at one extreme local AIDS community workers form part of the team, on the other, they are not involved at all. All of the members of the team in the groups who have direct contact with patients had taken basic counselling trainings.

Medications, medical supplies and material support, commonly available in the 6 Home Care Programmes are:-

(10)

Medications :- Broad spectrum antibiotic, antifungal, antiviral
antidiarrheal, ORS, analgesics anti-tuberculous, antimalarial, multivitamins, Iron, Cough syrup, antiemetic, antirheumatics, anti-histamines, Gentian violet, topical skin ointments, contraceptives
Bronchodilators, sedatives and herbal medicine.

Medical supplies:- medicine cups, disposable syringes & needles, disinfectant for injections, specimen bottle,

cotton, antiseptic solution, soap, bedding sheets, plastic sheets, dressing, bandages, gloves, condoms, apron.

Material Support :- Porridge (High energy), powdered milk, eggs soap, glucose drink, Rice, Barley, food formula, sugar, blanket, clothings, school fees, petty cash, money for starting income generating projects Bible.

Four of the programmes and not carry anti-tuberculous drug on the grounds that it should be treated in the hospitals. All of the programmes rely on funds from external donation, by some non-governmental organizations although to certain degree they also use local resources.

From the above review we can conclude that the programme is well accepted by the patients as well as by families because none of them rejected it after being involved. It is also possible to elicit that besides this it has multiple advantages such as the support itself for families to facilitate patient care, and the health promotional effect it has on the community in general. This was demonstrated in Chikaukata where, after the programme started, a study revealed that teenage pregnancy has decreased(10). This clearly implies how the programme has helped to modify attitudes and behaviours of the community.

Barriers to Home Based Care

According to the experience of the six programmes reviewed some of the barriers to the service are :- (10)

1. Lack of enough funds to make the programme sustainable.
2. Patients may not belong to the target group ie AIDS patients living in other non-covered areas.
3. There can be lack of knowledge of the programme by patients
4. Failure to refer patients to the programme
5. Lack of cooperation by hospital personal for example failure to inform the patient or discharging the patient before counselling.
6. Fear of stigmatization (for some programmes)
7. fear of the team (one programme)

The worst of all the problems is lack of enough funds to make the programme sustainable. This is because of the dependency on external funds for resources. Since the economic conditions of the countries is poor local resources are not dependable. Due to this factors the affordability of the programmes may decrease from time to time or may not be able to increase so that their coverage is increased.

Experience in Ethiopia

In Ethiopia OSSA was organized in 1987. It had a long term objective of providing community based social support to AIDS patients and short term objectives of providing, psychological, social and material support, to increase public awareness about AIDS, to increase promotion of safer sexual behaviour. The organization has started functioning since February 1993 by setting an office in Addis Ababa. Other than this organization there is a Catholic Mission called Home of Mother Theresa which gives Hospice Care for women AIDS patients. This programme provides lodgings to homeless female AIDS patients. Patients are referred to the programme from hospitals, by counsellors or physicians responsible for AIDS patients.

The delay in progress of a programme of such paramount importance is a sensitive point . As there are not many baseline studies done on Home Based Care, this study is expected to provide data and information usefull towards planning and implimentation of home based care . This study will reveal the acceptability of home care by assessing knowledge attitude and beliefs and responses ofthe study groups to practical aspect of the care.

III OBJECTIVE

To determine factors which can be challenges to Home Based Care for AIDS Patients.

Specific Objective

1. To assess level of knowledge of the Community, AIDS patients and AIDS patient's families , on causes , routes of transmission , and means of prevention of AIDS .
2. To determine the significanse of variability of attitudes and beliefs of the community, AIDS patients, their families and health workers on needs of AIDS patients in relation to hospital care vis avis home based care.
3. To determine the degree of acceptability of home based care by all groups through assessing their responses and attitudes towards the programme.
4. To outline further recommendation which can be used to as baseline, to improve and faster Home Care program, ,e for AIDS patients.

IV METHODS

1. Study Design

This is a descriptive - cross sectional study. It was done on four groups namely community, AIDS - patients, families of AIDS patients and Health Institution workers. Interviews were done using a separate prepared questionnaire for the community, AIDS patients, and families of AIDS patients , while for Health institution workers self administered questionnaires were used. The contents of the questionnaires were slightly different for each group on the questions about clinical settings .

2. Population

The study population was different for each group as discussed below but the study area was , as previously called Entoto Awraja, which comprised Kefitegna 11,12 and 13 (Now these Kefitegnas are named "Woreda" 11, 12, 13).

Group 1 - Community

The source population for the community survey was the population of Entoto Awraga. Out of these 33 kebeles, 10 were selected randomly, using the lottery method. Of these ten kebeles 4 were in Kefitegna 12, 4 were in kefitegna 13 and two of them were in kefitegna 11. Fifty households were selected from each of the ten

kebeles by systematic sampling by which the interviewer starts counting every 9th house starting from the kebele office. The directions as to where to start to go was also chosen randomly by lottery method from Right or left. From each of these 50 households, one person was randomly selected for the interview, by lottery method. A total of 489 respondents were interviewed for the study.

Exclusion Criteria

- Among the community members all who were below the age of 15 years were excluded from the study.
- Those household who have a family member with AIDS were also excluded . Such families were studied in a different group.

Inclusion Criteria

- All those who fulfilled the criteria and were willing to be interviewed well included in the study.

Group II - AIDS Patients

The source of the study population for AIDS patients were all AIDS patients present in 3 hospitals in Entoto Awraja, namely - Minilik II Hospital, St. Peter Hospital and Yekatit 12 Hospital. Although it was planned to interview 50 AIDS patients who are admitted in these 3 hospitals it was found out from the pilot study as well as the main study, that it will take longer time to get AIDS patients who are informed about their disease

status. Because of different reasons these patients are informed and get counselled at time of discharge. Due to time constraint it was difficult to wait until these patients get counselled, therefore they were selected from medical out patient departments while they came for follow-up visits. Among the AIDS patients who came for follow up visits those who were willing to be interviewed were selected after being asked for their consent by their physician, nurse or counsellor who knows their disease status and is following them.

As it was understood in all the three hospitals the physician nurse or counsellor who counselled the patient while on discharge will follow in subsequent visits. The patients met the investigator for the interview only after it was explained to them by their responsible physician and only after they agreed to be interviewed.

It was possible to get a total of 36 AIDS patients from O.P.D. while one patient who was readmitted was interviewed from the medical wards.

Exclusion Criteria

- All Those patients who do not know about their disease status .
- All those patients, even informed about their disease status are not residing in Addis Ababa .

Inclusion Criteria

- Those patients who fulfilled the inclusion criteria and

were willing to be interviewed were included in the study. The clinical conditions of the patients who consented to be interviewed were assessed by the responsible physicians before the interviewers.

Group III - Families of AIDS Patients

From the 37 AIDS patients interviewed , only six of them revealed their disease status to some members of their families . These patients were asked if they could permit the investigator to interview these family members. Although all of them were willing, the informed family member of one of the patients was not available, therefore from the rest of 5 patients who agreed it was possible to get 12 family members who were informed about the disease status of the patient to be interviewed. The rest of AIDS patients did not inform their family about their illness nor the health workers did.

Group IV - Health Institution Workers

The source population for the study group comprising health institution workers was all workers in 3 hospitals and 2 health centers found in Entoto Awraga. Among the health institution workers those who have more contacts with AIDS patients and involved in the hospital care process were chosen. Therefore, physicians, nurses, health assistants and cleaners who work in the medical wards and O.P.D. of the three hospital, Minilik II, St. Peter, and Yekatit 12 were included. Additionally same

category of workers from two Health Centres (H.C.) present in Entoto Awraga namely Shiromeda Health Center and Entoto Health Center also included in the study. As it was a self administered questionnaire, among the workers who could not fill in the questionnaire were left out, while those who were willing to fill were included.

3. Measurements

The questionnaire prepared for all the groups contained both open and closed ended questions. The questionnaires were prepared in English, then were translated into Amharic and again translated back to English.

Questions on the causes, transmission, and prevention of AIDS were used to measure the level of knowledge of the respondents. To assess their attitude towards AIDS, and AIDS patients, questions in relation to problems and needs of patients and their management were included. To elicit practices, items like visiting AIDS patients, type of support necessary for AIDS patients, risks of giving care for AIDS patients and volunteering for home care. Questions relating to AIDS as having supernatural cause, presence or absence of love in families of AIDS patients, were used to assess the respondents belief.

The above mentioned are only some of the questions present in the questionnaire which consists, on average

25 questions in each group ie. other than demographic discriptions . All the views and responses for knowledge, attitude, practice and belief questions of the different groups were estimated in frequencies and percentages.

4. Data Collection

The study was conducted through interview using a questionnaire which included both close and open ended questions. For the health Institution workers a self administered questionnaire was used. Nurses who were trained in counselling worked as interviewers of the famillies and coordinators for the collection of questionnaires from the health institution workers. High school graduates were recruited for interviewing the community members. Interviewers and other personnel who would be involved in the study after being recruited, were trained for 5 days by the principal investigator. During the training the participants were given all the necessary instructions and practised all the necessary procedures and requirement of the study, specially on precautions of handling interviews using a questionnaire which has mostly open ended and delicate questions.

Before launching the main study a pilot study was done for all study groups. The pilot study for the community subgroup was done by the community interviewers in 25 kebeles from 5 kebeles of kefitegna 21. The pilot

study for AIDS patients, families, and health institution workers was done in Black Lion Hospital and Zewditu Hospital.

Data collection of the community survey was done from January 4th to February 6th 1985. The self administered questionnaires were distributed starting from January 11. Interview of AIDS patients was started on February 15th. Except St Peter Hospital. Yekatit 12 and Minilik II Hospital were having clinics for follow-up visits of AIDS patients on 1-2 days/week therefore interview day and places were divided according to the follow-up clinic programmes of the hospitals.

The interview of AIDS patients was done exclusively by the principle investigator, and due to the fact that the interviewers had to be done in three different places within one week without utilizing all days of the week. In addition, counselled AIDS patients were rare even at out patient departments. This made it necessary to lengthen the data collection period for AIDS patients and their families extending it up to 1st week of April.

The collection of self administered questionnaires took equally lengthy time due to the delay by some of the workers in returning filled questionnaires.

During the community survey, the whole process was supervised daily by the investigator and other assigned personnel . Evaluative meetings were held once weekly

with all the interviewers where problem were discussed with the purpose of finding possible solution.

5. Data Analysis

Since the questions prepared for all study groups mostly contained open ended questions, the process of data analysis was started by coding all the different opinions and views of all respondents. It was necessary to reduce all these views to manageable categories by taking samples. Therefor sixty percent of questionnaires from the community interview, and the whole questionnaires from the rest groups were taken and then similar categories of views were merged . After the opinions were reduced and catagorised they were coded again. Thereafter , they were translated into English and entered into EPI5 version of statistical computer programme for annalysis .

Comparisons between different group as well as estimates within same group were done and precision of these estimates were determined by odds ratios, Chi-square and p-values. In addition to the questionnaire , personal observatitons of the investigator were also recorded and used as additional information.

6. Ethical consideration

As AIDS is a very sensitive issue when studies are done special considerations must be taken . For this study the followings are considered :

- Respondents consent : every respondent is included in the study only if the respondent is volunteer to participate. After assuring of utmost confidentiality and guaranteeing anonymity a verbal consent was obtained from the respondents .

- AIDS Patients - They were briefed about the purpose of the study at first by their following physician or counsellor. They encounter the interviewer only if they agree to participate in the study . For confidentiality purpose it was only the principal investigator who interviewed the patients .

Families - the same principle was followed to keep the confidentiality for the family members . For the two wives of patients who were among the respondents discussion about blood testing was carried out with them as well as with the responsible physicians and counsellors .

V RESULTS

There were a total of 661 respondents in the 4 groups studied out of which 485 were community members 127 were health institution workers, 37 AIDS patients and 12 from families of AIDS patients.

Although during the data collection from the community survey 492 questionnaires were returned, it was found out, during analysis, that 7 of the questionnaires lacked information in most of the questions therefore they were discarded. The rest 485 (97%) of the questionnaires were analysed.

1) Demographic Characteristics:

A- Community Members

From the community respondents 140 (28.9%) majority, were in the age groups of 20-24 years while 321 (66.2%) of the total respondents from this group were between the age category, 20-34 years. (Refer to table 1). Mean age was 28 years. Out of the total respondents 58% were male and 42% were females (Refer to table 1) 58% of the respondents attained school education up to grade 7-12. This is a high proportion and this is probably because, since the interview was done on voluntary basis perhaps most of the illiterates and those who are in lower grades did not volunteer to participate for the interview. It

is also seen that 31.6% (refer to table1) of the respondents are unemployed while 23.8% are students. Therefore it can be deduced that out of the respondents in the community there are considerable number of those who are 12th grade graduate .Sixty one percent of them were single and the majority were followers of the Orthodox religion (Refer to table 1).

B- AIDS Patients

Among the 37 AIDS patients, 14 (37.8%) were between the age groups 20-24 years (refer to table 1). Thirty (81%) were in the age group 20-34 years and the mean age for this group was 27 years. From all 12 (32.4%) were males and 35 (67.6%) were females. Seventeen (45.9%) of the patients have educational level of G 7-12, while there were 3 patients who were above grade 12.

Most of the AIDS patients interviewed were labelled as "others" which actually constitutes the majority of the patients occupation. In others included are 8 (21.6%) house-maids, 5 (13.5%) private institution workers and 2 are house wives. Majority of AIDS patients were house-maids being followed by government employers (refer to table 1). Out of the total patients interviewed 17 were single and all of them are followers of Orthodox religion. Thirty one of the patients were interviewed while they came for follow-up visits and only one out of the total 37, one was a patient who was counselled at

time of previous discharge but now readmitted in the wards. Twenty six (70.3%) of the patients stayed one or two months during their admission, 28 (75.6%) patients have spent less than 9 months since they were discharged (ref to table 4). As discussed earlier these patients were chosen for the interview they are well counselled, and have relatively adjusted themselves to their present condition. Some patients from the wards were counselled and were ready for discharge, but since it was their first counselling, they were considered to be unsettled. In addition to their outright rejection for the interviewed, their responsible physician and counsellors did not recommend them for the study so they were dropped from the study.

C- AIDS Patients Families

From the 12 AIDS patient families members, 4 were between the age group of 25-29 years, the rest were distributed between all age groups (ref to table 1). Mean age for this group was 32 years. Among the families members who are informed about the disease status of their family members, one was a father of the patient, two were mothers, three of them were sisters two of them were wives of patients, and four were brothers of the patients.

There was a husband who was informed of his wife's disease status, was not available for the interview.

Therefore there were a totally 5 males and 7 females in this group. Here again majority of them had attained school up to grade 7-12 (refert to table1). In this group's occupational status others include one on pension, two house-wives, and one person was working in private institution.

D- Health Institution Workers

Almost 60% of the respondents among health institution workers were general nurses and health assistants (refer to table 2). Majority of the respondants were from the hospitals since the number of workers was in higher amount , with relativevly fewer respondents from Yekatit 12 hospital , considering the number of health personel it has (Table-2).

Table 1- Demographic Characteristics of Respondents from community of Entoto Awraja , AIDS Patients and their families , and health institution workers from 3 hospitals and two health centers found in Entoto Awraja , Feb. 1993

Characteristics	Community Member N=485 # (%)	AIDS Patients N=37 #(%)	AIDS Patient Famillies N=12 #(%)	Health Inst. N=127 #(%)
AGE- 15-19	46 (9.5)	-	2 (16.7)	1 (0.8)
20-34	285 (66.5)	30 (81)	5 (41.6)	69 (54.4)
35-49	84 (17.3)	6 (16.2)	4 (33.3)	51 (40.1)
50-64	26 (5.4)	1 (2.7)	1 (8.3)	6 (4.7)
65 +	8 (1.6)	-	-	-
<u>TOTAL</u>	449 (100)	37(100)	12 (100)	127(100)
SEX- MALE	282 (58.1)	12(32.4)	5 (41.7)	54 (47.8)
FEMALE	203 (41.9)	35(67.6)	7 (58.3)	59 (52.2)
<u>TOTAL</u>	485 (100)	37 (100)	12 (100)	113 (100)
EDDUCATION				
illiterate	11 (2.3)	6(16.)	-	-
litracy	26 (5.4)	6(16.)	1 (8.3)	-
campaign				
Grade 1-6	61 (12.6)	5(13.)	2 (16.7)	-
7-12	285 (58.9)	17(45 9)	8 (66.7)	-
above 12	101 (20.1)	3 (8.)	1 (8.3)	-
OCCUPATION				
unemployed	153 (31.6)	2 (5.)	2 (16.7)	
daily laboror	11 (2.3)	2 (5.)	-	
student	115 (23.8)	5(13 5)	3 (25.0)	
comercial				
sex worker	3 (0.6)	2 (5.)	-	
government				
employee	101 (20.9)	6(16 2)	3 (25.0)	
merchant	26 (5.4)	3 (8.)	-	
bus/truck				

driver	15 (3.1)	2 (5.)	-
others	60 (12.4)	15(4 .5)	4 (33.3
<u>TOTAL</u>	484 (100)	37(1 0)	12 (100
MARITAL STATUS			
single	294 (60.6)	17(4 .9)	6 (50.
married	159 (32.8)	5(1 .5)	3 (25.0)
divorced/ separated	13 (2.7)	11(2 .7)	-
widowed	19 (3.9)	4 (1 .8)	3(25.0)
<u>TOTAL</u>	485 (100)	37 (100)	12 (100)
RELIGION			
Protestant	24 (5.0)	-	-
Catholic	7 (1.4)	-	-
Orthodox	431 (89.0)	37 (100)	12(100)
Moslem	20 (4.1)	-	-
no religion	2 (0.4)	-	-
<u>TOTAL</u>	484 (100)	37 (100)	12 (100)

Table-2 Hospital health Center workers by place of work and by profession- Entoto Awraja - Feb.1993

Profession	Minilk II Hospital	ST.Peter Hospital	Yekatit 12 Hospital	Shiromeda H.c	Entoto H.C	TOTAL	%
MD-Special-ist	7	-	8	-	-	15	11.8
General practitioner	4	2	4	1	2	13	10.2
Special-ist nurse	1	-	-	-	1	2	1.6
General nurse	12	6	5	6	5	34	26.8
Health assista-nt	7	8	5	8	10	38	29.9
Cleaner	2	9	4	2	2	19	15
Total	33	25	26	17	20	121	95.3

Table-3 Days of hospitalisation of AIDS Patients from 3 hospitals in Entoto Awraja - Feb. 1993

Days of hospitalisation	Frequency	%
less than 1 monthes	5	13.5
1-2 monthes	26	70.3
2-3 monthes	4	10.8
more than 3 monthes	2	5.4
TOTAL	37	100

Table-4 Number of monthes since discharged of AIDS Patients from 3 hospitals in Entoto Awraja- Feb. 1993

NO.Of Monthes	Frequency	%
Less than or equal to 3 monthes	9	24.3
4-6 monthes	11	29.7
7-9 monthes	8	21.6
10-12 monthes	3	8.1
More than 12 monthes	5	13.5
Still admitted	1	2.7
TOTAL	37	100

2. Results on Knowledge Questions

Generally it was found that the level of knowledge about AIDS, its causes, transmission and prevention is very high among all the groups. More than 80% of respondents from the community and families mentioned "Having Multiple Sexual Partner" as means of transmission of AIDS 93% of the community and 75% of the families mentioned "staying one to one" as a means of prevention, while more than 60% of the community and families, and 75% of the patients mentioned "using condoms" (refer to table 5).

Although 53% community, 83% AIDS patient families, and 75% AIDS patients said there was no cure for AIDS , there was a significant difference in proportions between those who said there is no cure and those who said there is cure comparing the community, families and patients (refer to table 5). There was no significant difference between the respondents for this question by their age,sex and educational level for the community (table 5). On the other hand when the community respondents were asked, how one knows he has AIDS 70% responded" when one has one of the signs and/or symptoms of AIDS such as diarrhoea, vomiting, loss of weight, appetite, fever.... " When Asked about source of information about AIDS 93% responded the radio, 49% T.V.

27% from health workers, 10% from news papers and magazines and 8% from friends. Health institution workers when responding to objectives of counselling 66% mentioned it to be for prevention of the patient from spreading the disease, 3% mentioned advises to patients so that they take care of themselves, 18% mentioned to give psychological support to the patient. Twenty four percent of the specialists and general practitioners mentioned about psychological support while 40% of the nurses and health assistants have responded similarly.

Table-5 Response to Knowledge Questions from community of Entoto Awraja , AIDS Patients , thier famillies and health instituttion workers from 3 hospitals and 2 health centers in Entoto Awraja - Feb 1993

	Community Member N=485		AIDS Patient's Famillies N=12		ASIDS Patients N=37	
	#	%	#	%	#	%
1)What causes AIDS						
Having multiple sexual partner	399	82.3	11	91.7	24	64.9
Using unsterilised instruments	75	15.5	9	75.0	16	43.2
Contamination ofinfected blood	33	6.8	7	58.3	5	13.5
HIV -Virus	40	8.2	2	16.7	0	00.0
I.D.N	23	4.7			7	18.9
Both-having MSP and using unsterilised instruments	70	14.4	9	75.0	14	37.8
2)How can one prevents AIDS						
Staying one to one	451	93	9	75.0	18	48.6
Using condoms	297	61.2	8	66.7	28	75.7
Using sterilied syringes& blades	88	18.1	10	83.3	1	2.7
Abstain from sex	4	0.8	-		8	21.6
Praying to God	7	1.4	-		—	
Using traditional herbs	7	1.4	-		—	
staying one to one only	184	37.9	-			

Both- staying oneto one & using condome	195	40.2	9	75.0		
3)Is there cure for AIDS						
NO	257	53.0	10	83.3	28	75.7
YES	185	38.1	1	8.3	5	13.5
I don't know	43	8.9	1	8.3	4	10.8

Table-6 Degrees of Association of responses for Knowledge Questions

Study Groups I-Community Memmbers
 II-AIDS Patients Famillies
 III-AIDS Patients
 IV-Hospital H.C Workers

Questions	Study Group	O.R	95%C.I	* χ^2	P-Value	
1)Priventi on of AIDS Staying one to one only	I, III	3.19	1.27-9.51	6.21	0.013	S
Using condom only	I, III	0.54	0.26-1.15	2.38	0.12	NS
Both	I, II, I II	2.44	1.04-5.92	4.24	0.04	S
2)Is there cure for AIDS NO/YES	I, III	0.25	0.08-0.69	8.05	0.005	S
	I, II, I II			13.48	0.001	S
	I-by educa tional level belowG r7 &above Gr7	0.65	0.38-1.10	2.47	0.1	NS
	I-by age	-	-	1.01	0.3	NS
I-by sex		0.68	0.45-1.02	3.43	0.06	NS

* χ^2 = Yates corrected

help. The difference in the responses between the different study groups are significant (Table 7&8). When the community study group were asked if patients with AIDS be isolated, 66% responded, they should, and this is because according to 58% of the total, in order to prevent spread of the disease.

There was a significant variation of opinion between the community and AIDS patients on the quality of Home Care as compared to hospital care. Two hundred seventy eight (57.3%) of the community respondents prefers Home Care, while only 3 (25%) of AIDS patients families and 15 (40.5%) of the patients did. Majority of the community respondents had the opinion that home care is better than hospital care . 20 % of them preferred home care because it gives more hope and decreases worries of the patient while 15% believed that it will be more comfortable at home to get more food and clothing. On the other hand ,37% of the health workers believed it is better if patients stay in hospital. The response of the health workers and the patients was similar (Table 7&8). Seven (58.3%) of the families of AIDS patients said that they will welcome visits of Home Care Team if it is composed of health workers, but if it is composed of volunteers from the community 7 of the 12 of them said they would not accept the team. Twenty of AIDS patients (68%) responded negatively to the question about families

3. Results on Attitude Questions

Four hundred eighty five (94%) of the community, 34(92%) of the patients, 113(93%) of the health institution workers and all of the families of patients responded that AIDS is not a problem of only one person (of the patient alone). Sixty percent of the community respondents answered it is not, because "it is also the problem of the family " while 64% of the patients responded negatively because the disease is communicable" (Table 7). Seven out of twelve AIDS patient families preferred the hospital to be the best place for terminally ill AIDS patients while all the community Patients and health workers responded equally between hospital and Home (Table7).

Sixty percent (296) of the community respondents believed that the needs of AIDS patients are not being met by hospital care but 31(83.8%) of patients and 11(91.7%) of the families believed the needs to be fulfilled. Similarly ,103 ((81.1%) of the health inistitution workers had the belief that hospital care do not fulfill the needs of AIDS patients. Majority of them attributed his to lack of drugs and instruments. (table7&8) Among the patients who did not agree about the fulfilment of needs by hospital care 5 reported that they had problems of getting enough food and one mentioned , problem of a person who could give personal

accepting Home Care Team. Sixteen(43%) of them responded negatively because they thought families wouldn't like the social problem which will be followed by the continuous visits of the Home Care Team. The families of the AIDS patients also had similar opinion (refer to table7&8). Thirty four of the 37 patients had the opinion that infact Home Care Team visits would attract attention of the neibhourhood and would expose them. There was similar finding with the AIDS patient families where 8 of them said secrets will be revealed. When the community respondents were asked about their reaction if someone get AIDS among themselves ,more than 68% responded they will be anxious, very sad ,shoked. Less than 5%, responded they will isolate the patient ; 33% mentioned the reaction of the neighbours will be isolation and/or hatred towards the familyly .

Table-7 Response To Attitude Questions from community of Entoto Awraja , AIDS Patients ,their famillies , and health institution workers from 3 hospitals and 2 health centers in Entoto Awraja -Feb. 1993

	Community Members N=485 # %	AIDS Patients families N=12 # %	AIDS Patients N=37 # %	Hospital Health Center workers N=127 # %
1)AIDS problem of only one person(patient alone)				
<u>Why NO?</u> The disease is communicable	123 25.2		24 67.7	Were not asked WHY?
It is also the problem of the family	293 60.4		5 13.5	

<u>Why YES?</u> Patient brought it by his own mistakes	20	4.1			No explanation	
2)Where do terminally ill patients prefer to die						
Hospital	161	33.2	7	58.3		43 33.9
Home	157	32.4	5	41.7		42 33.1
In an isolated place	43	8.9	-			3 2.1
Around Churches	31	6.4	-			1 0.8
3)Needs of AIDS Patients being met by hospital care						
<u>Why NO?</u> health workers are careless, exhausted	109	22.5	-			4 3.1
No cure for AIDS - Useless effort	78	16.1				4 3.1
Not enough drugs & instruments	31	6.4	1	8.3		61 48.0
Health workers are frightened of the disease	31	6.4	-			13 10.2
<u>Why YES?</u> Health workers will try thier best	84	17.3	10	83.3	28 75.7	4 3.1
4)Home Care better quality than hospital care	Asked as Better if patients could be cared at home					
<u>WHY YES</u> home care gives more hope	96	20	1	8.3	2 5.4	10 7.9
it is more comfortable	72	15	3	25.0	3 8.11	18 14.2
hospital is better	58	12	8	66.7	13 35.0	46 37
5)Home Care accepted by family of AIDS Patients	Not Asked		Home care team composed of 1-health workers 2-community			
NO			1=5 41.7 2=7 58.3		25 67.6	59 46.5

YES		1=7 58.3 2=3 25.0	7 18.9	49 30.4
I.D.N.		2 16.7	5 13.5	14 11.0
No answer		-		5 3.9

Table-8 Degrees of Association of Responses for Attitude Questions

Study Groups I-Community Member II-AIDS Patient Families
III-AIDS Patients IV-Hospital H.C Workers

Questions	Study Groups	O.R	95%C.I	X2	P-Value	
1)AIDS a problem of only one person	I,III	1.23	0.0-5.74	0.02	0.8	N.S
	I,II,IV			0.11(D.F2)	0.9	N.S
2)Needs of patients met by hospital care	I,IV	0.41	0.21-0.75	8.69	0.00	S
	I,III	15.14	5.81-	51.71	0.00	S
	I,III,IV	-	41.73	75.26(D.F2)	0.00	S
	IV-by proffn.	-	-	8.91(df=5)	0.11	NS
3)Home Care better quality than hospital care	I,III	0.47	0.22-0.99	3.90	0.05	S
	III,IV	1.16	0.51-2.67	0.04	0.08	NS
	I,IV	0.55	0.72-0.89	7.79	0.005	S
	I,III,IV			11.56(DF2)	0.003	S
4)Home care accepted by families NO/YES	III,IV	2.97	1.10-8.29	4.74	0.03	S
	III-by time of discharge	18.3	1.82-26.04	7.38	0.007	S

x2 = Yates corrected

4. Responses on Practice Questions

The community respondents were more positive, 427(88%) about visiting a relative who has AIDS in the hospital. 427 (88%) replied they would go and visit. But 33(89%) of the patients thought their relatives would not come and visit them if they know they have AIDS. There was a significant variation in the responses of these groups (Table 9&10). The patient replied that their relatives will be afraid to come and visit them if they know they have AIDS. There was also a remarkable difference between the community and the patients on the question of visiting a person with AIDS at home. 420 (86.6%) of the community said they would, while 32(87%) of the patients said, relatives will not come and visit them. This is so, for the same reason they gave for the previous question. On the other hand 39% of the community group responded, they were not afraid, since they know the transmission routes of AIDS. This response was not significantly different between different educational levels .

Among the Health Workers, 36 (28%) out of which 16 are MD specialists and G.P gave the opinion that there is no need to assign health worker specially for Care of AIDS patient while 83(65%) out of which 53 are nurses and health assistants thought there was a need. Among all the

health institution workers 33 (26%) said it will increase quality of care for the patients 15 (12%) said it will give protection to the health workers.

All the study groups were asked type of support needed for AIDS patients and families, and there was a significant difference between the opinions of all groups. The community respondents mostly stressed on the role of psychological and economic support (13.6, 50.1% respectively). The health workers emphasised mostly on health care (63%) while among the patients 15 mentioned money, 2 mentioned food, 2 mentioned they needed a place where they can stay, one mentioned the need of clothings while 17 responded they need nothing at the moment because either they are still working or families could support them (table 9). On the other hand families responded they do not need any help of any sort (58.3%) but when probed 41.7% replied economic support. In a study done in Uganda in Chikakanta in 1987 it was found out that 53% of the families , family income was reduced , usually because the main provider of the family was ill. In 39% the families' economical survival depended on help from other family or outside help and social support. Of 51 patients 9 were single mothers with little or no income 8, were totally dependent on family support (14).

Among all the respondents who were asked if they would volunteer for Home Care Team, 309 (63.7%) of the community members replied positively while 45 (54.3%) of the health institution workers replied to be volunteers. This was a significant difference in response (Table 9 & 10). There was no difference of response between different profession and by place of work among the health institution workers while there was significant difference of response between different levels of education ,by age and by sex, among community respondents (table 10) where among those who responded positively majority were males .

It was the opinion of 81% of health institution workers that families do not have enough home level nursing abilities to cope with the patients . More than 70% of the family respondents also had the impression that ,if the patient is staying at home they can take care of him except that they will have little to do if the patient get critically sick. Similar studies in Uganda in Chikakanta done in 1987 , has shown that 45 of 55 families visited at home needed nursing education on caring for the terminally ill(11).

According to 73(57%) of the health institution workers , common physical complaints of AIDS patients during admission , after their acute illness has subsided

, can be managed at home by the home care team , during their regular visits by carrying necessary , analgesics , antibiotics and psychotropic drugs. When the patients were asked their main complaints of illnesses at time of the interview , 15(41%) mentioned weakness, 7 (19%) mentioned cough with or without chest pain , 5 (14%) had headache , 4 (11%) had epigastric burning pain . Six (16%) of the patients did not have any complaints , they came only to continue thier follow up visits. Most of them are on anti-tubercular drugs .

While 80 (63%) of the health institution workers believed that volunteers of home care team will have dangers of acquiring the disease , only 36 (28%) thought the have no such risk . Similarly 90 (71%) of the workers believed that the team memmbres will have dangers of aquiring AIDS related diseases , and only 24 of them believed the team will have no such risk .

Table-9 Response To Practice Questions from community of Entoto Awraja , AIDS Patients , their families and health institution workers from 3 hospitals and 2 health centers in Entoto Awraja .

	Community Member N=485		AIDS Patients family N=12		AIDS Patients N=37		Hospital & H.C Workers N=127	
	#	%	#	%	#	%	#	%
1)Visit a relative with AIDS at home								
<u>Why NO</u> Bieng afraid of the disease	58	12.0			32	86.5		
<u>Why YES</u> I am not afraid to get the disease because I visited	188	38.8						
It is expected of a relative /to keep moral high	193	39.8						
3)Type of support for AIDS Patients & Families	asked as-what type of support are you willing to give		what type of support do you need at home		same as the family		what type of support be given by home care team	
Psychological	260	53.6	1	2.7	-		29	22.8
Social (physical help)	87	17.9	-		-		10	7.9
Economical (money, food,cloth...)	243	50.0	5	41.7	20	54.0	4	3.1
Health care /health- edducation	-		-		-		80	63.0
None	-		7	58.3	17	45.9		
4)Volunteer fort Home Care Team			Not asked		Not asked			

NO	170	35.1			69	54.3
YES	309	63.7			45	35.4
I.D.N	6	1.2			5	3.9
No Ansewr		-			8	6.3

Table-10 Degrees of Association of Responses for Practice Questions

I-Community Member II-AIDS Patients Family
 III-AIDS Patients IV-Health Institution Workres

Questions	Study Group	O.R	95 % C.I.	χ^2	P-Value	
1)Visit a relative with AIDS in the hospital NO/YES	I,III	0.02	0.01-0.06	133.93	0.000	S
	I- by age	-	-	0.16	0.7	NS
	I-by sex	1.13	0.63-2.00	0.08	0.5	NS
Visit a relative with AIDS at home	I,III	0.01	0.00-0.05	125.88	0.000	S
3)Special assignment of health workers for care of AIDS patients necessary NO/YES	IV by profession -MD-Special+GP and G.Nurses + Health Asst.	0.29	0.10-0.81	5.96	0.015	S
4)Volunteer for Home Care Team NO/YES	I,IV	0.36	0.23-0.56	22.96	0.000	S
	IV-BY profession	-	-	4.46 (df-5)	0.50	NS
	IV by place of work	-	-	3.32 (df-4)	0.51	NS
	I-By edducational level	-	-	46.04 (df-4)	0.000	S
	I-by age	-	-	46.04 (df-4)	0.000	S
	I-by sex	0.52	0.35-0.78	10.75	0.001	S

χ^2 = Yates corrected

5. Responses to Belief Questions

Majority of the community, families of AIDS patients and the patients themselves did not believe that the disease is thrust upon victims as a divine punishment. (297= 61%, 7=58% and 25=68% respectively). More than 60% of the respondent from the community and AIDS patients believed that the disease comes due to peoples bad behaviours or mistakes (Table 11&12).

There was also no significant difference among respondents when they were asked if family love still be present even in times for AIDS patient families. Two hundred and eighty one (57.9%) of the community, 30 (81.1%) of the patients and 92 (75.6%) of the health institution workers believed that there won't be family love (Table 11&12). Among the community members there was no significant difference in responses by age, sex and educational level, but there was a marked difference among health workers by profession (Table 12).

Table-11 Response To Belief Questions

	Community Member		AIDS Patients Families		AIDS Patients		Hospital H.C Workers	
	N=485 #	%	N=12 #	%	N=37 #	%	N=127 #	%
1)Disease thrust upon its victims as devine punishment								
<u>Why NO</u> Comes due to peoples bad behaviour, mis takes	295	60.8	4	33.3	25	67.6		
<u>Why YES</u> It has no cure	70	14.4	3	25.0	2	5.4		
Comes due to behaving against God's teachings	64	13.2	1	8.3	7	18.9		
2)Familly Love still well founded even in times for AIDS patient famillies			Were not Asked					
<u>Why NO</u> They will be sad & anxous,worry	171	35.3	-		13	43.3	33	26.0
They will be afraid to catch the disease	61	13.0	-		12	32.4	12	9.4
They will hate &,isolate te patient	87	17.9	-		4	10.8	9	7.1

Table-12 Degrees of Association of Respondants for Belief Questions

I-Community Members II-AIDS Patient Families
 III- AIDS Patients IV- Health Inst. Workers

Questions	Study Group	O.R	95% C.I.	χ^2	P-Value	
1)Disease considered as divine punishment NO/YES	I, III	0.72	0.32-1.57	0.51	0.48	NS
	II, III	0.62	0.13-2.89	0.13	0.72	NS
	I, II, III			0.88 (DF-2)	0.64	NS
2)Family Love still present even for time of AIDS Pt. families	I, III	0.34	0.11-0.95	4.31	0.04	S
	I, IV	0.62	0.38-1.02	3.48	0.062	NS
	I, III, IV	-	-	8.21 (DF-2)	0.02	S
	I-by eddc. level below Gr7	1.03	0.60-1.80	0.000	0.9	NS
	I-by age above Gr7	-	-	00.9	0.3	NS
	I-by sex	1.08	0.73-1.89	0.08	0.8	NS
	IV-by proffn. MD Sp+GP & Nurses+H.A	0.16	0.05-0.47	13.52	0.000	S

* χ^2 =Yates corrected

VI DISCUSSION

The objective of this study is to determine factors which influence and challenges Home Based Care for AIDS patients and support from their families. This was done through interviewer and using written questionnaires.

1. Demographic Characteristics

Out of 661 respondents from the 4 group involved in the study namely ,community memmbers, AIDS Patients, AIDS patient famillies, and health institution workers, the main bulk is consisted of the community study group (73%). Each group was studied and analyzed separately as well as together when necessary. Although majority of the community respondents had attained high school level of education, when stratified analysis were done level of education proved to be of no signifficance .

As the study about AIDS was a frightful, and sensitive subject it was decided to do it on volunteer basis. Therefor it was necessary to obtain respondents informed consent before the interview. During the community survey despite long explanations , people were reluctant or even refuse to participate. Those who volunteered for the interview were those who have formal education, mostly high school level. This may demonstrate that there is some kind of fear, specially

among those who are illiterate to discuss issues about AIDS with an unknown person (the interviewers).

The fact that the disease AIDS is affecting the young and economically productive groups was shown in this study, where 81% of the patients are between the age group 20-34 years. As it was seen in previous studies and AIDS surveillance reports done by institutions many did not include "House Maid" as one category . In this study out of 37 patients 8 have claimed to be house maids(which has the highest number among others), may show that, these patients maybe concealing their real occupation, or more so, "House maids" may be a potential category to have for AIDS patients. It is a well known fact that those women who work as house maids change job from time to time and may work in a Tella, or Tej seller shop for some time and return to house maids jobs again and again or possibly engage in commercial sex practice .

Out of the 37 AIDS patients 36 of them were from the O.P.Ds of the three study hospitals. This is because all of the admitted patients who have AIDS, were unaware of their disease status, and will only be told at time of discharge. During the study it was found out that except Yekatit 12 Hospital, the other two hospitals are not doing pre-test counselling. According to the attending physicians and counsellors the pre-test counsellings are

not done, to avoid unwanted circumstances such as rejection of patients by families, default by patients on their own will, and sometimes discrimination of the health staff.

The results of post-test counselling are delayed until the time of discharges for the same reasons mentioned above. It was also observed by the physicians, that the patients condition appeared to deteriorate when they are told about results.

Form the six AIDS patients who have informed about their illness to one or more family member, three had pre-test counselling, one of the patients family were informed even before the patient new about it, and the rest (two) told their families after they knew the result. All respondants told their families eventhough they were told to keep the results highly confidential by their physician and counsillors. All of them answered they found it necessary to inform their family. But those who were given pre-test counselling had enough time to prepare themselves and adjust to the condition, therefore it was relatively easier for them to reveal this condition than those who had no pre test counselling. Among the patients interviewed the one who was still admitted, was very sad and in despair. Similarly those who had stayed for less than 3 months after being discharged behaved the same way while those who had

stayed for more than 6 months after discharge were more hopeful. This illustrates that, AIDS patient needs more time, to accept the condition they are in, and to adjust to it. Pre-test counselling helps the patient to familiarize to the coming frightening truth. The advise of the health workers and counsellors also helps a lot for the patients in this aspect.

It is very important to mention here that 13 out of 37 patients had no relatives around, to care for them when they were admitted. This considerable number of patients are the types who should be getting Home Based Care .

Eventhough one of the main disadvantages of self administered questionnaire is low respondent rate in this study it was observed to be satisfactory in that the response rate of health institution workers was more than 90% . The reason for non participating in the study was either unwillingness, not understanding most of the questions (especially cleaners and few health assistants who could not read well) or to not being present during the distribution of the questionnaires for distribution of health workers by profession and place of work refer to table .

2. Knowledge Questions

Any AIDS strategy must take into consideration the mentality of the people , the degree to which they have acces to information and education . In this study generally it was observed that there is high level of knowledge about AIDS among the community. Most of the respondents know how AIDS is transmitted and how it is prevented. There was a general confusion between the questions about the cause of AIDS and the transmission routes of AIDS. More than 80% of the respondents gave similar answer to both questions identifying cause of AIDS as routes of transmission of AIDS. Similar findings were reported in a study done in Ghana in 1990 where 60% of respondent from the community confused these questions (17). In another study done in Tanzania, Uganda, and Zaire to search for community based solution to the AIDS crisis in 1991 AIDS was found to be the major health problem in all the three countries but it was also observed that, misconceptions concerning the etiology and the transmision of AIDS existes in all the three countries and hamper AIDS work. Common beliefs such as AIDS being a curse from God or the result of witchcraft were associated with the stigma and fear(18). This shows low level of understanding of the community for biological causes, of the disease. It was shown that while more than 80% of the respondent from the community

and AIDS patient families responded that the cause of AIDS is by having multiple sexual partner, among the patients only 64% of them responded the same way. When also asked about prevention of AIDS, while more than 90% of the Community and 75% of the families gave "staying one to one" as an answer, only 48% did among the patients. This is evidence of reluctance on discussing behavioural aspects of the disease by the patients.

Among the community respondents, 70% mentioned having chronic diarrhoea, vomiting, fever, loss of weight and other physical signs as indications for having AIDS. Although this might be true, when one considers multiple causation of the above mentioned signs and symptoms, the reported high frequency may lead to labelling of people wrongly. This will also create difficult social encounters for the wrongly labelled people. After all the above mentioned symptoms may be of AIDS of another kind "Acquired Immune Deficiency Syndrome" (19) On the other hand, radios and T.V. played major roles in transmitting information about AIDS to the community. There was a similar finding in a study done in Arba Minch Town which revealed health personnel having lower rates than observed from this study (20).

Majority of the health workers emphasised on control of the disease than on psychological support. Eventhough controlling the disease is also one of the fundamental

components of counselling for AIDS patients, the psychological support has more important role in the general management of the patient as well as having indirect role in helping from spreading the disease. The respons ofthe health proffesionals on the objective of counselling showed that there is more awareness of the importance of psychological support among the nurses than the medical doctors.

3. Attitude Questions

It was observed that there is a general tendency to view AIDS as a problem of not only the patient alone but also the family and the community as whole. Although there is little difference of opinion among the patients and the community as to why they say it is not a problem of the patient alone, it is a very encouraging finding that there is a base, of seeing the problem in its universal mode, and therefore, readiness of sharing it by the community. The response on prefered place for terminalli ill AIDS patients revealed that majority o respondants mentioned, the places in relation to where its is best to acquire terminal care ie - Hospital and Home. At this point, the responses have touched the different spectrum of care, required by terminal patients, including health care, social and psychological care, as part of Home Care. Most of the patients and family members had the opinion that , hospital care meets

the needs of AIDS patients. This may be because these groups were interviewed in hospitals while the patients were seeking medical care, therefore this situation may have inadvertently influenced them to respond in that way. But the community respondents and health institution workers, did not believe that hospitals fulfils all the needs of AIDS patients. This question reflected that the community do not have good attitudes towards health workers, and considers them as not fulfilling their duties. The health institution workers have strengthened this opinion in an indirect way, by attributing it to the unavailability of enough drugs and instruments. Generally all the opinion were revolving around patients, hospital, and health care only. Only few respondents mentioned other needs of the patients which requires consideration such as social, material and psychological needs. This signifies the fact ,educational programs planned for the public as well as health workers , emphasise on sensitising more on clinical nature of AIDS than on social issues.

On the other hand five of the AIDS patients have reported that they had problems of getting enough food, and one mentioned, problem of a person who could give physical help during their admission . Not less than 10% of the health institution workers admitted that health workers will be frightened of AIDS patients and therefore

give less care. This response was not affected by profession or place of work. Such a response may not be surprising as it is generally believed that health workers should be in fact more frightened than any other persons. But it gives a warning as to how much problem with the discrimination of the patients by health workers will cause, as the pandemic increases .

On the issue of Home Care "head-on"-it was the opinion of majority of the community respondents that it has better quality than hospital care. But most of the health institution workers preferred the patient to stay in the hospital . Only 3% mentioned about psychological relief patients get while staying at home and only 6% believed that, the patients will get more food and clothing. It is apparent that, the community is perceiving, AIDS patient needs from different angles, from health care to material, and psychological needs while the health workers visualize the needs only around clinical care.

The attitudes of the patients towards home care was similar to that of health workers. They feel that it won't be like hospital care but, their main worry was, the social consequences that will follow if they were visited by such a team. The families on the other hand preferred the team, if it is composed of health personnel rather than if it is composed of volunteers from the

community. Therefore, these results illustrates that there is tremendous amount of fear of social stigma by the patients, and families alike . The health workers also hold the same opinion: 26% of believed that families, will not welcome the team due to fear of social problem.

In contrast to the above observations when asked about reaction of the family if someone get AIDS among themselves, majority of the community group responded they will be anxious, very sad, shocked, only very small number responded they will isolate the patient. They also mentioned that the reaction of the neighbours will be isolation and /or hatred towards the family . Eventhough there is some fear, and stigma among the community respondents, it is not that serious. It is not obvious, wether the fear and stigma, is primarily originating from the health institutions and being inflicted upon the patients, as well as their families. But from the above observations it is signified that AIDS is stigmatised, through fear mostly by health workers ,and through feeling of shame which was manifested as fear of social isolation or fear of being exposed by the community and to a higher degree by the patients and famillies. One way or another the fact that 34 out of 37 AIDS patient, 8 out 12 family members, having the opinion that the continuous visit of Home Care

Team will help in revealing their secrets about the presence of an AIDS patient require detailed analysis and study to come up with, ways which such programmes could be more accepted by the patients as well as their families. The attitudes of the health workers towards the programme can be considered as potential challenge for further study and action.

4. Practice Questions

In the above section, it was shown that, there is difference in the magnitude of presence of stigma as fear, between the community and AIDS patients. In this section also similar finding will be discussed in relation to visiting a relative who has AIDS, in the hospital as well as at home. Majority of the community respondents were willing to visit, because they are not afraid, they know the transmission routes. Majority of the AIDS patients thought that their relatives would not come and visit them because they will be afraid of the disease. The difference in magnitude of presence of fear and stigma between the community and the patients, is demonstrated. Sixty three percent of the community respondents identified psychological problems and considerable number of the respondents identified, social problems and only few mentioned economic problems as, difficulties faced by AIDS patients and for difficulties of the families of AIDS patient, majority mentioned

economical problem. On the other hand, majority (44%) of the health institution workers mentioned social problems as difficulties of AIDS patient and families. Seventy three percent of the patients themselves identified economical problems. Type of support they would give/needed, had responses of similar trends except that health institution workers replied by enlarge, to give health care.

It was, encouraging to observe that generally wide spectrum of type of support were mentioned, by the respondents even including spiritual supports like prayers even though mentioned by quite a few. It was the opinion of 81% of the health institution workers that families do not have enough home, level nursing abilities to cope up with the patients. Most of the family respondent also had the impression that , they would not have enough ability to care for the patient especially if the patient get seriously ill . These opinions are to some extent, discouraging self efficiency and self empowerment of the family, which is the greatest source of strength for the patient, and the function of the family as responsible unit.

According to the response of most health institution workers and patients , the current complaints of the patients regarding illnesses , were observed to be manageable by home care visits . But still most of the

health institution workers feared that volunteer of home care team will have dangers of acquiring the disease. Their opinion was similar on the home care team acquiring AIDS related diseases. Subsequently when they were asked if they could volunteer for a Home Care Team majority said they would not, 34% said they would, and 14% of respondents gave no answer which may possibly mean they would not volunteer. On the other hand among the community respondents 86% replied they will give support to AIDS patients staying at home, 64% also replied they will volunteer for home care team if they were asked. The implication of these finding, is that the attitudes of the health workers towards the Home Care programme is to be studied further , since they are part of the home care team, more explanation, and educational programmes are mandatory, to change the attitudes of the health workers.

5. Belief Questions

It was observed that generally the level of knowledge of the respondents about AIDS is high. Additionally more than 60% of them did not believe that the disease came as a result of divine punishment, and actually mentioned the occurrence of the disease, due to peoples bad behaviour, and mistakes. This reflects that the disease more often is diagnosed in emperical rather than in magico religious catagories .

Although majority of the respondent did not believe that there will be no family love in families where there is an AIDS patient, the proportion who had this opinion were higher among the health institution workers than AIDS patients. Here again the presence of fear among the two groups is observed to be high while it is less in the community. But generally the presence of psychological problems, which were attributed to the absence of family love. Only very small number of respondents mentioned isolation or rejection of patient by families as reason to decrease family love. This finding has the implication that generally, there will be despair, anxiety, or even rejection or isolation of the patient by family members not necessarily the result of fear of contracting the disease .

If we analyze the above results that the high level of knowledge, good attitude and high level of positivity towards practice questions it will make us consider the reaction of the family towards the patient which in most cases, may not be of being afraid of acquiring the disease, but it may be because family members, do not know how to cope with a person with AIDS, they will be in despair when they have to cope with a person who is dying, they will feel awkward, they will be embarrassed and therefore withdraw from the whole subject by labelling it as fear of contracting the disease. In fact

in this study this fear was not observed to be present in a considerable degree, except from the health institution workers and AIDS patients.

6 The study - This study was designed so that the questionnaires include more of open ended questions. Although it is all well known fact that questionnaires of high flexibility, requires more time, and money, and are very difficult to analyze, types questions were prepared because, as the topic "AIDS" is very sensitive, with much fear and stigmas associated to it was felt that open ended questions will help in collecting in depth informations about knowledge, attitudes, Behaviour and practices, and it will help to explore spontaneous remarks of respondents.

For the health institution workers due to anticipated time shortage written questionnaires were used in addition to permitting anonymity so that respondents could give honest responses.

The Limitations of this study are :

1. The topic is sensitive and respondents were chosen strictly on voluntary basis, which therefore has caused, the community respondents to be more of one type than describing a general population type.
2. High flexibility questions - tends to elicit great deal of repetition of opinions, requires good training of interviewers who are able to probe for

more opinions and who could be able to know and record opinion which are acceptable.

3. Written questionnaires have caused to miss some respondent because it could not be used on illiterates and those who do not volunteer. It also has caused some misunderstanding of the question by few respondent

VII CONCLUSION

From what has been observed and discussed, from this study, the following conclusion have been reached.

1. One of the goals of the study was to assess the level of knowledge and understanding of the community, AIDS patients and their families about AIDS and aspects related to Home Care. It was found out that, there is high level of knowledge about AIDS, by all the groups. All the groups were able to identify at least two important means of transmission of the disease and two, means of prevention. The level of knowledge of the health institution worker on objectives of counselling was also satisfactory where majority of the respondents mentioned at least two of important functions. But more emphases was given by these respondents on prevention of spread then on psychological support which is equally or even more important aspect of counselling of AIDS patients.

The community respondents described signs and symptoms which are non-specific as indicators for a

person to have AIDS. This means more educational activities is required because the labelling of a person as having AIDS when one loses weight due to a number of factors will have a lots of unwanted social consequences. Although it is quite encouraging to observe this high level of knowledge among the respondents one must bear in mind that high level of knowledge about AIDS helps a lot in prevention of AIDS but knowledge alone has been proven not to do much in different studies like in a study done in Arba Minch, where it was revealed that there was a statistical significant association between knowledge about the role of condoms in AIDS prevention, compared to use by sexually experienced respondents. In this study it was observed that among those who knew about condoms 52% never used it (20). In another study in Rwanda in 1987, women attending a hospital, were asked on knowledge, attitude and practice questions. When HIV, positivity test was also conducted, high level of knowledge was observed but there was also high % of HIV positively (21). Therefore with change of knowledge attitude changes and most importantly behavioural changes must also occur to have maximum effect.

2. The other goal of the study was to assess the

attitudes, practices and beliefs of the respondents on needs of AIDS patients in relation to hospital care and Home Care. In general there was an encouraging observation . All the respondents believed that AIDS is a problem not only of the patient but of the community as a whole. It was also possible to elicit that the attitudes of the community respondents was rather negative towards health workers and hospital care while they had positive attitude towards home care. The community respondents have shown their acceptance of the Home Care by responding more positively to attitude as well as practice questions. The results from this survey also implies that although some kind of despair or embarrassment was shown generally , there was little fear of AIDS patients, by the community group. On the other hand while the health institution workers have the opinion that not enough is being done for AIDS patients, they also do not have positive attitude towards Home Care. Much fear, and sceptism was elicited from the health institution workers about the programme. They showed this by answering negatively to most of practice questions.

The fear, of Home Care was also observed on the patients and families. Although this

might be expected, especially from the patients and families, this study showed that there is difference in the perception of the health workers about the community. Due to this gap of perception, health institution workers might be contributing to increase the already present fear and stigma of AIDS, on themselves primarily, then, on to the patients and also families either directly or indirectly.

3. From the study it was elicited that, the needs of AIDS patients are multiple, and they are not being met by hospital care. The community respondents were more concerned with the complexity of needs of AIDS patients, while the health workers, responded more emphasizing on clinical care. When one analyzes the present complaints of the patients themselves and those as given by the health professionals, it can be concluded that these complaints could be managed at home by the team, by supplying different drugs during regular visits. Most of the patients expressed their need of economical support and, considerable number also had said they do not have any family around. All these finding implies the urgency by which the programme is required .

VIII RECOMMENDATION

Based on the results , discussions and conclusions reached from this study ,the following recommendations are made.

- 1) More health education activities for the community is required specially about the signs and symptoms of AIDS as well as aspects of its biological cause so that people's awareness will increase . This will help to smoothen the process of pre- test counselling which is little practiced at the moment , It is important for the patients , families as well as the whole community in limiting the spread of the disease and , in early detection of type of support patients require such as psychological ,social or economical.
- 2) From this study ,the other important conclusion is, the attitudes of health institution workers being a potential barriers to the programme by inflicting exaggerated fear on the patients as well as families and community as a whole. This needs

a campaign by all who are responsible, especially Ministry of Health , Department of AIDS Control (DAC) which has been launching tremendous campaign to increase the awareness of the community about AIDS . Now it is believed that this is the time to change strategies . It has been shown that the level of knowledge of the community is considerably high. Beliefs and Attitudes , according to this study have also been modified to certain extent. Therefore what remains is to change behaviours. The change of behaviours needs to be studied quite intensively . The greatest challenge is changing the attitudes , and beliefs of health workers . This up to now has been given little consideration. Educating the community how frightening AIDS is, by using many fearsome stories and pictures , will only increase the fear and stigma. Health educators now have to be aware that at this level of knowledge , ways need to be found to change behaviours, rather than inflicting more fear and stigma. The fear and the stigma inflicted by health workers also have to be eliminated by

planning more promotional activities for health workers .Health workers must have the chance to voice their fear ,discuss their feelings and ask whatever questions they have . Such repeated practice will eliminate the misconception and modifies their attitude with time. If through promotional activities attitudes are changed ,functions of counselling will be smooth . There will be more practise on giving necessary support to AIDS patients .Promotional activities should be by all means supported by enough drugs and instruments which helps in protection against spread towards, community as well as health workers themselves.

- 3) This study by no means covers all the necessary information required for such an important programme .Special study on AIDS patients and Families is recommended to be done in a different set up , so that , the respondents will not be influenced by the interviewer or the place of interview .More in-depth study is required to outline the attitudes and beliefs of health workers on hospital care and Home Care.

- 4) Nationally- There are some Non - Governmt. Organisations which provide hospice care for AIDS patients like Mother Theresa - a Catholic mission organisation which gives lodging facilities for female AIDS patients . By the chairmanship of Department of AIDS Control ten religious and non-relligious non-govt. organisations met nin February 1993 and organized a Home Care Programme called Organization for Social Servises for AIDS, (OSSA)by setting an office. Although this step is encouraging it is the recommended that it is very essential to fasten the process by which the programme could be put into practice. The National Control of AIDS under the Ministry of Health in their second medium term plan which goes from 1992-1996 (22) some activities were planned of which mostly are social mobilisation and training . But the urgency of the need for home care by patients is becomming very high that it is recomended these plans be put in practice.

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CONSENT FORM I

We thank you very much for allowing us share your precious time , to give a brief explanation about a study which is going to be conducted in this hospital/ health center .

This study will involve persons who are working in the medical wards and medical OPDs . The study will be conducted through this self administered questionnaire . The study involves , various question related to AIDS and AIDS patients . Some of the questions have multiple choices where you can choose ONLY one of them and circle the number which corresponds to your choice. Most of the multiple choice questions are followed by request for more explanations in the allocated spaces .

Since your answers have a great contribution to the study we hope they will be complete and true. We want to assure you that your answers and results of the study will be kept in a strictly confidential way. As the name of the participant is not necessary , your name will never be mentioned in relation to this study either now or in the future . You have a full right not to participate or leave any questions which you do not want to answer.

Are you willing to participate Yes _____

No _____

Annex 1

Questionnaire on Aids - Home Based Care

I. Questions for Hospital/Health centre workers.

Respondent

No _____

Date _____ Age _____ Sex:1-male 2-female

Place of work _____

hospital/ health centre ward _____

Profession _____

Type of Responsibility in the
ward _____

A. Questions on AIDS Patients and their Management

1. What is the total number of beds in your ward? _____

What is the total number of patients? _____

what is the total number of AIDS patients in your
ward? _____

2. What are the most common reasons for admission of
AIDS patients at your wards? (Diarrhoea, Skin infection,
Tuberculosis)

3. What is the average stays of patients with diseases
other than AIDS _____

What is the average stays of patients with AIDS _____

4 Do you believe that AIDS is a health problem of the patient alone? 0-No 1- Yes

5. What do you think are some of the problems faced by AIDS patients and families?

6. Do you think that hospitals provided all the needs of the AIDS patients during their stay in the hospital? 0-No 1- Yes (please explain)

7. Do you think that AIDS management requires special skills and altitudes which are best learned at the job? 0-No 1- Yes

8. Do you believe that special assignment of professionals is necessary for the proper management of AIDS patients ? 0-No 1-Yes

(please explain)

9. What are the objective of counselling services for AIDS patients?

10. Should counselling include other family members ,

aunts, neighbours, friends....?

11. Do you believe that most AIDS patients should pay for their stay in the hospital?

12. Where do most admitted AIDS patients, who are terminally ill prefer to die?

13. How many of AIDS patients you have been managing have been totally rejected by their families ? 0- none 1- some 2- most

14. What do you think are the reasons for rejection ?

15. How many of AIDS patients you know ended up being discharged even though they may still be unwell 0-None 1- only few 2.some 3. most

Do patients prefer to stay longer upon recommended discharge ?

(please explain)

16. Do you believe that traditional values of Ethiopian families such as family love is still well founded even in time for AIDS families?

17. What are most common physical complaints of patients with AIDS during their stay in hospital? ie. after initial illness has been treated?

18. Do you believe these most common complaints of AIDS patients can be managed at home by:-

- Having regular home visits ,taking necessary drugs & solutions and doing proper wound management ? 0- No

1- Yes 2- I don't know

- Patients have to come to hospital for any conditions ?

0-No 1-Yes 3-I don't know

B- Questions about Home Based Care

1. Have you heard of any home based care programme for AIDS patients ? 0- No 1- Yes 2. I.D.N.

2. Are you at present involved in any activities of home based care programme ? 0- No 1- Yes

3. Do you believe that home based care programme can alleviate most of the needs and problems in the management of AIDS patients?

4. Do you think families of AIDS patients will welcome visits by home care team? 0- No 1- Yes 2- I don't know (please explain)

5. Do you think that such programme will be accepted by the community ? 0- No 1- Yes 2-I don't know (please explain)

6. Do you believe that families of AIDS patients have enough home level nursing abilities for caring patients with AIDS ?

7. What type of care do you suggest should be given on home based services ?

8. Who should be involved in the home care team ?

9. Do you believe that home care will increase the quality of life for the patient ?

10. What do you think are the dangers of home care for AIDS patients and their families ?

11. What type of AIDS patients do you think are appropriate for treatment in non-hospital setting such as "home"?

12. To what extent do you think that volunteers of home care team have dangers of acquiring AIDS ? 0- None 1- small 2- high

3- Very high To what extent do you think that volunteers have dangers of acquiring AIDS related diseases such as Tuberculosis, hepatitis, typhoid ? 0- None 1- small 2- high 3- Very high

13. If asked are you willing to volunteer for home based care team?

CONSENT FORM II.

We thank you very much for allowing us to share your precious time for a brief explanation about a study to be conducted in this hospital .

This study will involve AIDS patients who are informed about their disease status and who are counselled . This study will be conducted through an interview . The questions involves various intimate and private life matters . We would like to assure you that the results of the interview and the study shall be kept in a strictly confidential way . Since the name of the participant is not needed for the study , your name will never be mentioned in relation to the study either now or in the future .

You have a full right not to participate in this study or, stop at any time during the interview .

Are you willing to participate ? Yes _____

No _____

Questionnaire on Home Based Care for AIDS Patient

II. Questions to AIDS Patients

Date _____ Hospital/Health centre _____

respondent No _____

A. Demographic Characteristics

1. Age: _____ 2. sex 1-male 2-female

3. Address: Kefitegna _____ kebele _____

House No _____

4. Education: (circle one) 0- Illiterate 1- literacy
campaign 2- Grade 1-6 3- Grade 7-12 4- Above
grade 12-a-Certificate b-Diploma c-Degree

5. Occupation:- 0- unemployed 1-daily labourer
2- student 3- commercial sex worker 4- government
employee 5- merchant 6- bus or truck driver 7- previous
army 8- others _____

6. Marital status: 0- single 1- married 2- divorced
or separated 3- widowed

7. Religion 1- protestant 2- catholic 3- orthodox 4-
moslem 5- no religion 6- other

8. How many days have you been hospitalized ? _____

B. Knowledge about AIDS

1. What causes AIDS ?

2. Give some of the means of transmission of AIDS.

3. Do you think that AIDS can be cured ? 0- No 1- Yes
2- I.D.N.

4. How can you prevent AIDS ?

5. Do you believe that the disease is thrust upon you by
fate as punishment ? 0- No 1- Yes 2- I.D.N. (please
explain)

6. Do you believe that modern medical treatment is of
any use in treatment of AIDS? 0- No 1- Yes 2- I.D.N.
What other type of treatment do you recommend ?

7. Do you think AIDS is a problem of only one person ?
0- No 1- Yes 2- I.D.N. (please explain)

8. Did you getting the care you expected from the
hospital ?

9. Who was caring for you while you were staying in the
hospital. (family, neighbour, friends)

- Will they care for you if they know you have AIDS ?

10. Do neighbours come and visit you ? 0- No 1- Yes
2- I.D.N.

How about friends ? 0- No 1- Yes 2- I do t know

How about relatives ? 0- No 1- yes 2- I don t know

11. Do you have any other member of the family who has
AIDS ? 0- No 1- Yes 2- I do t know If yes who ?
(brother, sister, aunt)

12. What is your current complaint, symptoms ?

13. What do you feel at this moment ?

14. Who payed for your stay in the hospital ?

If it was not free do you think you could afford to
pay ?

15. Do you believe that traditional values of Ethiopian
families such as family love is well founded even in time
for AIDS families?

C. Questions about Home Care

1. Are you wiling to stay in the hospital as long as
necessary ?

2. Do you prefer the treatment and nursing care to continue at home if possible ?

3. Do you think that your family will accept and support nursing care at home ?

4. What other support do you require at home ?

5. Do you believe that home care will be accepted by your neighbours ?

6. Do you think that home care will have better quality than hospital care ?

7. Will you accept a regular visit by a home care team at your home ?

Will you family accept such a visit ?

8. Do you think that a regular visit by a home care team will attract attention of the neighbourhood to yourself and your family?

9. Do you think that the visit will dispel many misconception, fear and rumours about the disease through the regular visit and education ?

10. If you stay at your home will neighbours come and visit you ?

How about relatives ?

How about friends ?

What about if they know your disease status ?

11. Who know about your disease status from your family?
(parents, husband, wife ...)

12. Do you agree that we should discuss with your family members who are informed about your disease status, about similar questions we have been discussing with you ?

D. High Risk Behaviours

1. Did you have intercourse with other than your regular partner?

0- No 1- Yes If yes how many in a month ? _____
in two months? _____

2. Did you have intercourse with commercial sex workers?

0- No 1- Yes If yes how may in a month ? in two months?

3. Did you have any history of sexually transmitted diseases in the last 1-1/2 year 0- No 1- yes If yes can you specify or describe?

4. Have you had any blood transfusion ? 0- No 1- Yes
3- I.D.N.

[If the response to questions no. 1&2 is "No" DO NOT ASK No 5.

5. Did you or your partner wear condom when you have intercourse with other than your regular partner? 0- No
1- Yes some times 2. Yes most of the times 3. yes always

CONSENT FORM III

We thank you very much for allowing us to share your precious time for a brief discussion about a study to be conducted in Entoto Awraja .

This study will involve a total of 500 systematical selected house holds from 10 kebeles in the awraja . The ten kebeles are also selected randomly . From each house hold only one person who fulfils the inclusion criteria is taken for the study by random selection. Therefor you are included in the study strictly by chance and no other means .

The study will be conducted through interview using a questionnaire which has questions pertaining to AIDS and AIDS patients . We would like to assure you that the results of the interview and the study will be kept strictly confidential .Since your name is not required for the study it will never be mentioned in relation to the study , either now or in the future . You have a full right not to participate in this interview , or stop at any time you want during the interview .

Are you willing to participate? Yes _____

No _____

Questionnaire for AIDS-Home Based Care

III. Questions for AIDS Patient Families and Community

Members

Date _____ Respondent no _____

A. Demographic Characteristics

1. Age _____
2. Sex (circle one) 1- male 2- female
3. Address kefitegna _____ Kebele _____
house No _____
4. Education. 0- Illiterate 1-Literacy campaign 2- Grade 1-6 3-Grade 7-12 4-Above grade 12-a-certificate b-Diploma c-Degree
5. Occupation 0- Unemployed 1- Daily labourer 2- student 3-commercial sex worker 4- Governmental employee 5- Merchant 6-bus or truck driver 7- previous army 8-others _____
6. Marital status 0- single 1- married 2- divorced or separated 3- widowed
7. Religion 1- protestant 2- catholic 3- orthodox 4- moslem 5- no religion 6- other _____

B. Knowledge about AIDS

1. What is the leading health problem affecting men and women in Ethiopia to day ?
2. What causes AIDS ?

Questionnaire on AIDS Home Based Care

Ci. Questions on AIDS Patients and Home Care for

Community Members (as continuation from part III)

1. Do you know some one with AIDS ? 0- No 1- Yes

If Yes who ? (friend, relative, Neighbour ...)

2. Would you continue to visit a friend or relative living with AIDS at a hospital ?

What about at home ?

3. Would you continue to visit families of AIDS patient at their home ? (please explain) 0- No 1- Yes (please explain)

4. Do you think that patients with AIDS should be isolated ?

0- No 1- Yes (please explain)

5.If a person was tested for AIDS should be isolated ?

6. Should a spouse of a person who has turned out to be positive be notified of the test result ? 0- No 1- Yes 2- I.D.N. (please explain)

Questionnaire on AIDS Home Based Care

Ci. Questions on AIDS Patients and Home Care for

Community Members (as continuation from part III)

1. Do you know some one with AIDS ? 0- No 1- Yes

If Yes who ? (friend, relative, Neighbour ...)

2. Would you continue to visit a friend or relative living with AIDS at a hospital ?

What about at home ?

3. Would you continue to visit families of AIDS patient at their home ? (please explain) 0- No 1- Yes (please explain)

4. Do you think that patients with AIDS should be isolated ?

0- No 1- Yes (please explain)

5.If a person was tested for AIDS should be isolated ?

6. Should a spouse of a person who has turned out to be positive be notified of the test result ? 0- No 1- Yes 2- I.D.N. (please explain)

7. How would a family react if they learned that the husband has positive blood test ?

8. What would be the reaction of your family if someone in the family gets AIDS ?

What about the neighbours ?

9. What do you think are the difficulties of AIDS patients ?

What about their families ?

10. Do you believe that AIDS is a problem of only one person?

11. Do you believe that the traditional values of Ethiopian families such as family love can still be well founded even in times for AIDS families ?

0- No 1- Yes 2. I.D.N. (Please explain)

12. Where do you believe that terminally ill AIDS patients should die ?

13. Do you believe that the needs of AIDS patients are being met by hospital care team ?

0- No 1- Yes 2. I.D.N. (Please explain)

14. Do you believe that it is better if patients with AIDS could be cared at home by regular visits from home care team ?

(efficiency, relevance, acceptability) 0- No 1- Yes

2. I.D.N. (Please explain)

15.If there happen to be an AIDS patient who is staying at home will you give support to the patient and families?

0- No 1- Yes (please explain)

If yes what type of support will you give ?

16. If a volunteer is required from the community for a home care team, to have a regular visit for AIDS patients do you think you can volunteer to be part of the team ?

0- No 1- Yes 2- I.D.N. (please explain)

Questionnaire for AIDS Home Based Care

cii-Questions on AIDS Patients and Home Care to AIDS Patients' Families (as continuation of Part III)

1. Do you think that the member of the family with AIDS is benefiting from the stay in the hospital ? 0-No 1-Yes 2- I.D.N. Please explain)
2. Do you believe that hospital care provides all the needs for the AIDS patients ? 0- No 1- Yes 2- I.D.N. (please explain)
3. Can the patient or family afford to pay for the stay in the hospital ?
4. What problems have the family faced due to the illness of the family member ?
5. What problems have the family faced due to the illness of the family member ?
6. Have you ever suggested of taking the patient home ?
0- No 1- Yes (please explain)

7. Do you think your family has the ability for giving care for the patient ? 0- No 1- Yes 2- I.D.N. (please explain)

8. Do you think your family has the ability for giving care for the patient ? 0- No 1- Yes 2- I.D.N. (please explain)

9. Do you believe that home care will increase the quality of life for the patient ? 0- No 1- Yes 2- I.D.N. (Please explain).

10. Where do you think that terminally ill patients should die?

11. Will your family welcome a regular visit by home care team which is composed of health professionals ? 0- No 2- Yes (please explain)

What if the team is composed of community members from the neighbourhood? 0- No 2- Yes (pleases explain)

12. Will a regular visit by a home care team attract attention of the neighbourhood to your family ? 0- No
1- Yes 2- I.D.N. (please explain)

13. Do you think a regular visit by such a team will alleviate the fear and mis-conception of the neighbours and the community? 0- No 1-yes 2- I.D.N. (please explain)

14. Do you had your family go and visit, friends, neighbours or relatives as before? 0- No 1-Yes (please explain)

15. Have you any other family member who has AIDS? 0- No
1- Yes (father, mother, brother, sister, aunt...)

16. What kind of support do you expect from the community ?

17. Home facilities A, water 0- Not available 1. own pipe water 2- Share piped water with neighbours 3. gets from municipality distribution center
4. other specify _____

B, Latrine 0- No latrine available 1. Own flush latrine 2. flush latrine share with neighbours 3. own pit latrine 4. Pit latrine shared with neighbours 5.

Pit latrine communal 6. open field

C. House condition i) separate room, for the patient can
be accommodated 0- No 1- Yes

If no ii) Isolation of the patient in times of diarrhoea
or open wound can be provided 0- No 1- Yes

Volunteers for home based care 0- No 1- Yes

2- I.D.N. (please explain)

D. High Risk Behaviours

1. Did you have intercourse with other than your regular partner?

0- No 1- Yes If yes how many in a month ? _____
in two months? _____

2. Did you have intercourse with commercial sex workers?

0- No 1- Yes If yes how may in a month ?
in two months?

3. Did you have any history of sexually transmitted diseases in the last 1-1/2 year 0- No 1- yes If yes can you specify or describe?

4. Have you had any blood transfusion ? 0- No 1- Yes
3- I.D.N.

[If the response to questions no. 1&2 is "No" DO NOT ASK No 5.

5. Did you or your partner wear condom when you have intercourse with other than your regular partner? 0- No
1- Yes some times 2. Yes most of the times 3. yes always

