

**ASSESSMENT OF KNOWLEDGE, ATTITUDES  
AND PRACTICE ON HOME BASED CARE OF  
HIV/AIDS PATIENTS IN BUTULA DIVISION, BUSIA  
DISTRICT**

**By**

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## **Dedication**

This work is dedicated to my family in recognition of their support and cooperation during my study.

**Declaration**

I hereby declare that this dissertation is my original work and has not been presented to any University in the world for the award of Masters Degree in Public Health.

Signed,

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<b>Table of contents</b>	<b>Page</b>
Dedication	j
Declaration	jj
Acknowledgement	jjj
Table of contents	iv
List of Figures	viii
List of Tables	ix
Definitions of concepts used in this study	x
List of abbreviations	xii
Summary	xiv
<b>Chapter 1: Introduction</b>	<b>1</b>
1.1: Overview oh HIV/AIDS	1
1.2: HIV/Aids situation in Kenya	2
1.3: Organisation of Health sector in Kenya	5
1.4: Home based care in Kenya	7
<b>Chapter 2: Literature review</b>	<b>12</b>
2.1: Overview	12
2.2: Knowledge, skills and practice	13
2.3: Attitude, stigma and community support	15
2.4: Socio-economic impact on home based care	20
2.5: Description of REEP's Home based care in Busia	21
<b>Chapter 3: Research problem and justification</b>	<b>26</b>
3.1: Main objective	28

3.2: Specific objectives	28
3.3: Hypothesis	28
<b>Chapter 4: Methodology</b>	<b>29</b>
4.1: Study location	29
4.2: Study population	30
4.2.1: Socio-cultural system in Busia district	30
4.2.2: Food security in Busia district	31
4.2.3: Education situation in Busia District	32
4.2.4: Health situation in Busia District	32
4.3: Study subjects	35
4.3.1: Inclusion and exclusion criteria	35
4.4: Study design	35
4.5: Selection of subjects	36
4.5.1: Sampling methodology for quantitative data	36
4.5.2: Sample size	
4.5.3: Selection of participants for qualitative data	37
4.6: Data collection	37
4.6.1: Structured interviews	37
4.6.2: Focus group discussions	38
4.6.3: In depth interviews	38
4.7: Variables	
4.7.1: Independent variables	39
4.7.2: Depended variables	39

4.8: Data analysis and processing	39
4.8.1: Qualitative data	39
4.8.2: Quantitative data	40
4.9: Quality control and research integrity	40
4.10: Ethical issues	41
3.11: Limitations of the study	41
<b>Chapter 5: Results</b>	<b>42</b>
5.1: Socio demographic characteristics	42
5.2: Level of knowledge on home based care	47
5.2.1: Knowledge scores on home based care	55
5.3: Skills and practices	56
5.4: Community attitudes and support towards home based care	65
5.5: Relationship between socio democratic characteristics and knowledge, attitudes and practices	72
5.5.1: Knowledge	72
5.5.2: Attitude	74
5.5.3: Practice	78
5.6: Results of logistic regression analysis	81
<b>Chapter 6: Discussion</b>	<b>83</b>
6.1: Socio demographic characteristics	83
6.2: Knowledge and skills on home based care	92
6.3: Attitudes stigma and community support	96



6.4: Food and socio economic support	103
6.5: Nursing care and counseling and community support	107
6.6: Treatment and referral support	110
6.7: Sustainability of home based care programme	115
<b>Chapter 7: Conclusions and Recommendations</b>	<b>118</b>
7.1: Conclusions	118
7.1.1: Knowledge	118
7.1.2: Attitude and community support	118
7.1.3: Practices	119
7.2: Recommendations	120
7.2.1: National level	120
7.2.2: District level	120
7.2.3: Community level	121
7.2.4: Sustainability	122
7.2.5: Further research	123
<b>References</b>	<b>124</b>
<b>Appendices</b>	<b>136</b>
Structured interview questionnaire	137
In depth interview guide	144
Focus group discussion guide	148

<b>List of Figures</b>	<b>Page</b>
Figure 1 Age of Respondents (in years)	42
Figure 2 Religion of respondents	43
Figure 3 Level of Education of respondents	44
Figure 4 Marital status of respondents	45
Figure 5 Occupation of respondents	46
Figure 6 The source of information on home based care	48
Figure 7 Response to diseases managed by home based care	50
Figure 8 Channels of community education about home based care	51
Figure 9 The components of home based care	52
Figure 10 Persons involved in home based care discussions	55
Figure 11 Persons nursing PLWAs	57
Figure 12 Practice of nursing PLWAs	58
Figure 13 Sources of gloves	59
Figure 14 Reasons for continued referral of PLWAs to hospital	62
Figure 15 Opinion on HBC by respondents	65
Figure 16 Reasons for PLWAs not accessing services	69

## List of Tables

Table 1	Distribution of health facilities in Busia district	34
Table 2	Sex of respondents	43
Table 3	Duration of widowhood	46
Table 4	Awareness of home based care by respondents	47
Table 5	Institutions providing home based care	49
Table 6	Advantages/benefits of home based care	54
Table 7	Categorized knowledge scores on home based care	56
Table 8	Existence of referral system for PLWAs	60
Table 9	Reduction in referrals due to home based care	61
Table 10	Access of medication by the HIV/Aids patients	63
Table 11	Categorized scores on practice of home based care	64
Table 12	What communities want for PLAWs	66
Table 13	Acknowledging PLWAs in the community	68
Table 14	Relationship between socio demographic variables and knowledge on home based care	74
Table 15	Relationship between socio- demographic variables and attitude towards on home based care	77
Table 16	Relationship between socio- demographic variables and practice of home based care	80
Table 17	Logistic regression analysis between the levels of education and knowledge on home based care	82

## **Definitions of key concepts**

### **1) Knowledge**

The facts, information, understanding and skills that a person acquired through experience or education.

### **2) Attitude**

A way of perception/opinion about somebody or something or a way of behaving towards somebody or something.

### **3) Beliefs**

What one accepts as real and true. Usually what is held true at cultural or peer level

### **4) Practices**

A way of doing something that is common, habitual and expected by individuals, the family and/or community.

### **5) Aids**

Acquired immune deficiency syndrome, a progressive, ultimately fatal condition (syndrome) that reduces the body's ability to fight infections. It is caused by infection with human immunodeficiency virus (HIV)

### **6) Home based care**

Care of Aids patients at home. It comprises of, counseling (both psychological and spiritual), balanced nutrition, nursing care, treatment of opportunistic infections, and referral system to health facility involving community health workers and family.

### **7) Sexually transmitted infections/diseases**

The term given a group of diseases affecting both men and women, affecting mostly the genitals and generally transmitted during sexual activity.

### **8) Referral**

Sending sick persons from the home or community to a health facility (hospital, health center and dispensary) or other care service, or from the health facility to the community.

### **9) Opportunistic infections**

Infections and diseases that take advantage of HIV weakened immune system like Tuberculosis.

### **10) Community health worker**

A trained person, often a volunteer, who works within the community to teach people about health practices, provides some simple treatments, and refers sick people to health facilities for better treatment.

### **11) Increase in knowledge**

Increase in knowledge: The mean score on home based care knowledge that is greater than and significantly different from average score (6 out of 11 scores)

## List of abbreviations

AIDS:	Acquired Immuno-deficiency Syndrome
ART:	Anti retro viral Treatment
CACC:	Constituency Aids Control Committee
CBO:	Community Based Organisations
CDF:	Constituency Development Fund
CHWs:	Community Health Workers
CIDA:	Canadian International Development Agency
DACC	District AIDS Control Programme
DFID:	Department for International Development
GDP:	Gross Domestic product
DHBCC:	District Home Based Care Committees
DHMT:	District Health Management Team
DMO:	District Medical Officer
DO:	District Officer
FAO:	Food and Agricultural Organization.
FGD:	Focus Group Discussion
HBC:	Home Based Care
HBCF:	Home Based Care Fund
HIV:	Human Immuno deficiency Virus
IEC:	Information, education and Communication.
IMR:	Infant Mortality Rate.
KDHS:	Kenya Demographic Health Survey.

KVOWRC: Kenya Voluntary Women Rehabilitation Center.

MOH: Ministry Of Health

MPH: Masters of Public Health

MMR: Maternal Mortality Rate

NACC: National Aids Control Council

NASCOP: National Aids/STI Control Programme

NHIF: National Hospital Insurance Fund

NGO: Non-Governmental Organization

OR: Odds Ratio.

PACC: Provincial Aids Control Committees

PLWAs: People Living With Aids

REEP: Rural Education and Economic Enhancement Programme

SADC: South Africa Development community

STD: Sexual Transmitted Diseases.

TB: Tuberculosis

TOT: Trainers of Trainers.

VCT: Voluntary Counselling and Testing

UNAids: Joint United Nations on HIV/Aids

UNDP: United Nations Development Fund

UNICEF: United Nations Children Fund

USAID: United States Agency for International Department.

WHO: World Health Organisation

WFP: World Food Programme

## Summary

In Busia District, Western Kenya, the estimated HIV prevalence is 14.2% (NAS COP, 2005), with 90% of people living in rural areas where access to medical facilities is inadequate. The number of people falling ill as a result of HIV infection is rising dramatically regardless of existing prevention efforts. Since AIDS is a chronic disease lasting months or years, home based care is increasingly the option of choice for care for PLWAs. In response to the growing demands the HIV epidemic has placed on the people and communities in Busia, community health workers have been trained to provide home-based care to sick or dying PLWAs in rural areas. The purpose of this study was to assess knowledge, attitudes and practices in home based care of PLWAs patients in Butula division, Busia district. A descriptive cross-sectional study was carried out among the rural communities (n=393) comprising of CHWs, widows, PLWAs, caregivers and other community members randomly selected. Data was collected using both quantitative and qualitative methodologies. The level of education of respondents was found to be highly associated with knowledge on home based care ( $X^2 = 24.43$ , p value =.000). Those with no formal education were almost five times (OR=4.513) more likely to have inadequate knowledge on home based care as compared to those with tertiary education.

Fifty two percent of the respondents had adequate knowledge, which was a significant increase ( $z = 15.01$  with  $p < 0.05$ ) from 30% (REEP's baseline). This translated into 50% of respondents practicing good skills in nursing and counseling of PLWAs. Fifty percent still practiced poor nursing skills owing to



high turnover of trained CHWs (no incentives), limited refresher trainings and lack of logistical backup due to budgetary constraints. Referral of patients to health institutions was reported by 66% of respondents to be norm, although stigmatization was said to be rife in these institutions.

The attitude towards home based care was found to be positive (77.6 %), with 98.6% of the respondents saying that PLWAs should be given sympathy, material support, care and love at home. This has not translated into corresponding reduction in stigma due to prevailing poverty, overstretching of the traditional cushioning structures and caregiver burden/burnout. This affects mostly the women, who are the primary care givers amid limited resources.

### **Major conclusion**

From the study, it can be concluded that, although attitudes of communities are positive this is yet to translate into adequate knowledge, skills and good practices to care for PLWAs at home, amid prevailing poverty, caregiver burnout and limited training for CHWs/caregivers.

### **Major recommendation**

Initiating home based care fund or allocating specific funds from community development fund (CDF) for community groups while operationalising the district home based care team and Constituency Aids Control Committee (CACC) to mobilize communities and additional funds for continued CHW training and incentives. Introduction of health insurance for all through National Hospital Insurance Fund (NHIF) should be reconsidered at national level.

# Chapter 1 INTRODUCTION

## *1.1 Overview of HIV/Aids*

Human Immuno Deficiency Virus (HIV) causes a complex of signs and symptoms in man that are collectively known as Acquired Immuno deficiency syndrome (AIDS). This syndrome was first observed in homosexual men in the United States in the late seventies. The virus was isolated in the United States in 1981 and the first case to be diagnosed in Kenya was in 1984. Since then, the disease has spread in Kenya, Africa and all over the world to form one of the worst pandemics ever known in man's history (*NASCOP, 2005*).

Thirty four million people in Sub - Sahara Africa have been infected with HIV; eleven and half million of these people have already died. One quarter of the 11.5 million people were children. Seven out of every ten of newly infected people live in Sub - Sahara Africa. Among them are children under the age of 15 years (*UNAIDS, 2000*).

Without preventive therapy, up to one third of the babies delivered by infected women will become infected and most of these children will die before the age of 8 years. In Zimbabwe surveillance programmes, about half of all pregnant women are found to be infected with HIV. At least one third of these women are likely to pass the infection on to their babies either via perinatal transmission or breast-feeding (*UNAIDS, 2000*).

Over 22.5 million men and women are presently living with HIV in Africa. There is no single country in sub Saharan Africa that has escaped this grave disease, however the number of cases among sub-Saharan countries are significantly

high, with some countries being far worse off than others. In South Africa, Malawi, Mozambique, Rwanda, and Zambia, infection rates are from 1 in 7 people to 1 in 9 people. In central Africa, Namibia, Swaziland, and Zimbabwe, the ratio is 1 in 6 people. HIV/AIDS has become a major public health problem and human crisis in Africa straining heavily on health care and social services resources far beyond the capability of the sub-Saharan African countries (UNAIDS, 2000).

## **1.2 HIV/AIDS situation in Kenya**

It is estimated that about 1.5 million people in Kenya have developed AIDS and died since 1984, leaving behind close to one million orphans. Currently, Kenya is losing about 300 people daily to HIV/AIDS, which is approximately 12 deaths per hour! The cumulative number of AIDS deaths is estimated to increase from over 300,000 in 2001 to 2 million by 2010 (NACC 2000).

By December 2000, it was estimated that close to 2.5 million Kenyans out of the country's population 28.5 million (1999 Census) were living with HIV/AIDS. Current estimates of HIV prevalence suggest that in urban areas the rate of HIV is about 9.7%, or 421,000 HIV-infected adults. HIV prevalence in rural areas is increasing rapidly and in 2003 there were approximately 5.2% of the adult population infected. Because 80% of Kenyans live in rural areas, these percentages translate to approximately 636,000 million infected adults in rural Kenya (NAS COP, 2005).

Voluntary HIV counseling and testing (VCT) is not well established in Kenya with testing facilities available only at the national, provincial and some district hospitals. Therefore, these figures are thought to be considerably lower than the actual number of people living with HIV/AIDS in Kenya (*Ministry of Health, 1999*). Sentinel surveillance systems are in operation in 25 urban sites and 11 peri-urban and rural sites around the country. These sites are all in antenatal clinics where blood is drawn to test for syphilis. Once the test for syphilis is performed all personal identifiers are removed and the serum is tested for HIV. This provides information on HIV that is unlinked to the person. Each year 200-300 pregnant women are tested for HIV in this unlinked fashion from each site. The sero-positivity of women in antenatal clinics in 1998 ranged from a high prevalence of 20-35% in some areas to as low as 4-10% in others. Estimates from these figures are used to assess the overall HIV infection rate in Kenya.

It is noted that 75% of those infected by HIV/AIDS live in the rural areas and the majority are young people aged between 15-39 years. All Districts and Municipalities in Kenya are reporting increasing numbers of new HIV infection daily. (*WHO, 2000*).

The magnitude and impact of HIV/AIDS in Kenya is not just a major public health problem and development challenge but is increasingly creating severe negative socio-economic impact.

A 1992 study (*Forsythe et al. 1992*) estimated the cost of hospital care for an AIDS patient at Kshs. 27,200/-. The Sessional Paper No. 4 of 1997 on AIDS in Kenya (*Ministry of Health, 1997*) estimates the direct cost of treating a new AIDS

patient at Kshs. 34,680/- while indirect cost (lost wages) amount to Kshs. 538,560/-. This brings the estimated total cost of AIDS (direct and indirect) to over Kshs. 573,240/- per patient. The direct cost of AIDS comprises of the cost of drugs, laboratory tests, radiology and hospital overhead costs while the indirect costs encompasses the average productive life-years lost.

*Nalo and Aoko (1994)* estimated that by the 2000 the potential cost of providing treatment for AIDS would equal the entire 1993/94 recurrent budget of the Ministry of Health. The analysis further noted that in 1991, the total cost of AIDS to the country ranged between 2 and 4% of GDP but that this would increase to 20% by the year 2010. The rising cost of AIDS is extremely worrying for a low-income country such as Kenya, having per capita income of only US\$280.

The demand that AIDS puts on health services can also be illustrated by looking at hospital beds. Not all people with AIDS seek hospital care. But for those that do, the average length of stay is considerably longer than for most other diseases, perhaps as long as 60 days of hospital stay. In 1992, as much as 15% of all hospital beds in the country were occupied by AIDS patients. *Ngugi (1995)* estimated bed occupancy rates for HIV/AIDS-related opportunistic diseases at adult wards in major urban hospitals including Kenyatta National Hospital at 30%, while in district hospitals bed utilization for the same illnesses ranged between 10 and 30%. However, the study noted that significant differences existed, with Kisumu and Busia Districts recording bed occupancy rates by HIV/AIDS-related illnesses as high as 70%. Such a demand for beds for AIDS patients greatly constrains hospital facilities, undermining the normal operations. As the

epidemic grows, so will the hospital bed requirements. By 2000 about half of all hospital beds were required for AIDS patients. This has left insufficient number of beds for patients with all other complaints.

The realisation that Kenya is losing about 300 of its people daily to HIV/AIDS has led the top political leadership to declare HIV/AIDS a National Disaster. When addressing Members of Parliament in Mombasa in November 1999, retired President Daniel Arap Moi declared AIDS a National Disaster and stated that "AIDS is not just a serious threat to our social and economic development, it is a real threat to our very existence. AIDS has reduced many families to the status of beggars. No family in Kenya remains untouched by the suffering and death caused by AIDS. The real solution to the spread of AIDS lies with each and every one of us" (*Nation Newspaper 25 th November 1999 pg 1*).

These growing demands need urgent attention in order to mitigate the devastation of social and economic impact of HIV/AIDS, such as, increased infant mortality, massive expenditures to hospital care and prohibitive drug costs. These are major challenges that pose a security risk to this emerging new democratisation process in Kenya.

### **1.3 Organization of the Health Sector in Kenya**

The major players in the health sector reform include members of the Ministry of Health and the Ministry of Local Authorities. Other players are non-governmental organizations (NGOs), faith-based organizations and the private sector. Health services are delivered through a network of approximately 4200 health facilities with the public health system accounting for 51 % of the total. This total

comprises of 218 hospitals, 575 health centres, 2523 dispensaries, 191 nursing and maternity homes, and 707 health clinics or medical centres (*Ministry of Health, 1999*). According to 1996 statistics, for every 100,000 Kenyans there were 14.1 doctors, 2.4 dentists, 5.1 pharmacists, 25.2 registered nurses, 83.2 enrolled nurses, 10.9 clinical officers, 2.0 public health officers, 14.9 public health technicians, and 3.4 pharmacy technologists (*Ministry of Health, 1999*). In addition to the public health system, there are a number of agencies that provide funds to NGOs, and religious organizations, etc. The most notable funding agencies include UK DFID, the World Bank, USAID, CIDA, the Swedish and Norwegian Red Cross and the Japanese government.

The health system is designed much like the hub and spokes of a wheel (*WHO, 2000*). In the centre is the main referral hospital of Kenya, the Kenyatta National Hospital. In addition, there are eight provinces in Kenya, and each has a referral hospital that in turn refers to the national hospital. There are also a series of sub-district or district hospitals within each province that refer to the provincial hospital. Each district also has a succession of health centres. The most peripheral health care facilities are the dispensaries. These dispensaries are located within 4-5 kilometres of each village or community, and are considered to be within walking distance. Throughout this health care system, there are also a number of private health facilities, religious organizations and non-governmental organizations.

The health centres are the first line of referral from the dispensary. These health centres are staffed by a registered nurse/midwife, who is responsible for maternity care. There is also a clinical officer who has a diploma in clinical medicine and diagnoses and treats patients. Each health centre also has a records officer, and some health centres have laboratory and pharmacy technicians, although this is not universal. Other staff that might be available at the health clinics include medical social workers, children officers, public health officers, orthopaedic technicians, and nutritionists. The health centre usually has about five beds for maternity care. These beds can also be used in an emergency if a patient is to be transferred to a district or provincial hospital. Each health centre has a vehicle for transportation.

The dispensary is at the periphery of the health care system, and functions as a primary care facility, providing both curative and preventive health care. These dispensaries are supposed to carry basic drugs and supplies, although these supplies are often unavailable. In addition, they have standard kits that they sell for a small fee which is levied for transportation, drugs and supplies. However, if the patient is destitute, it is sometimes possible to waive these fees, or provide them at a reduced cost.

#### **1.4 Home Based Care in Kenya**

In order to meet the challenges posed by HIV/AIDS, the Government of Kenya recognized the need for the establishment of clear policy guidelines and effective organizational structures. As a result, in 1996 a national HIV/AIDS policy



framework began. This AIDS prevention and care framework was presented in 1997 with the goal "to provide a policy framework within which AIDS prevention and control efforts will be undertaken for the next 15 years and beyond" (*cited in NASCOP, 1999, p. 47*). Some of the key aspects of this policy framework included the participation of all sectors of society, taking into account socio-cultural issues, legal and ethical challenges, and the particular needs of women, men, youth and young adults, and children. The National AIDS and STDs Control Programme (NASCOP) was created within the MOH, with the mission statement "to provide a policy and strategic framework for mobilizing and coordinating resources to prevent HIV/AIDS transmission and provide care and support to the infected and affected people in Kenya" (*NASCOP, 1999, p. 50*).

The roles of the government in home based care according to the National Home based care programme and service guidelines, May 2002 is to:

- Create a supportive policy environment
- Develop policies and guidelines
- Develop and maintain standards
- Provide/coordinate training
- Provide drugs and commodities like kits

The Government of Kenya sets out the Aids control frame work through the National Aids Control Council (NACC), which has overall responsibility for monitoring and supervising HIV/Aids related activities. Among other functions, NACC, mobilises resources, formulates policy and strategy and develops information systems and collaborates with international and local agencies. Also

at national level, each ministry has an AIDS control unit to coordinate the implementation of the strategic plans within and across sectors. National Aids/STD Control Programme (NAS COP) is the Aids control unit in the Ministry of Health and is mandated to coordinate HIV/Aids activities between ministries and supervise home based care programmes. Under NACC, there are Provincial Aids Control Committees (PACCs), then District Aids Control Committees (DACCS) and Constituency Aids Control Committees (CACCS) who are most relevant to the immediate needs of home based care programme. The CACCS are mandated to do community mobilisation, resource mobilisation, initiation of income generating activities, networking, monitoring and evaluation. The Aids Control Committees are supposed to collaborate closely with District Health management Teams (DHMTs), District Home Based Care Committees (DHBCC), local and District hospitals, health centres and NGOs/CBOs that are providing home based care.

In June 1993, the Ministry of Health (MOH) developed national guidelines in community home based care. However, these guidelines have not been made operational due to lack of funds. Consequently, a formal system of community home based care has not been implemented by Ministry of Health in Kenya yet. However, there are a number of Non Governmental Organisations (NGOs), religious organisations and donor agencies engaged in the provision of home based care throughout the country. Despite the lack of coordination in home based care, there have been sporadic government sponsored home care initiatives. For example, in 1999-2000, fifty people were trained in home based

care in the districts of Nyando, Kisumu, Rachiony, Kuria and Migori. In addition, 24 people received a diploma in home based care in Nairobi and Central provinces. These training programmes were conducted by personnel from Mildmay International, in collaboration with University of Nairobi and the Kenya Voluntary Women's Rehabilitation Centre (KVOWRC). Although these training programmes were helpful in sensitising the health care personnel to the care and support needs of people at home, due to lack of government funds, these trainings have not been maintained.

The national AIDS and STD control Programme (NAS COP) has developed guidelines for the implementation of eight home based care pilot projects in each of the eight provinces of Kenya (NAS COP 1999). In particular, the guidelines have four components, namely;

- Clinical management, with early diagnosis, rational treatment and planning for follow up for HIV related illness.
- Nursing care services that promote and maintain good health, hygiene and nutrition.
- Counselling and psychological support, including stress and anxiety reduction, promoting positive living, and helping individuals make informed decisions on HIV testing, planning for the future, and behavioural change involving sexual partners in decision making.
- Social support, information sharing, referral support groups, welfare services and legal advice for individuals and families.

The objectives formulated from these guidelines for home-based care are:

- To facilitate the continuity of patient care from the health facility to the home and the community.
- To promote the family and community awareness of HIV/AIDS prevention and care.
- To empower the family and the community with knowledge to ensure long term care and support.
- To raise the acceptability levels of PLWAs by family and community, hence reducing stigma associated with HIV/AIDS.
- To streamline the patient referral from the health institutions to the community, and from community to appropriate health and social service facilities.
- To facilitate quality community care to the infected and affected persons.

Home based care programmes are already evident in some districts in Kenya where the prevalence of HIV/Aids is high, notably Kisumu, Siaya, Thika, Mombasa, Busia and Nakuru districts. Non Governmental Organisations (NGOs) and Community Based Organisations (CBOs) have taken a lead role in initiating home based care to supplement the efforts of the Ministry of Health. One of the NGO involved in the provision of home based care in Butula Division, Busia District is Rural Education and Economic Enhancement Programme (REEP). Under this organisation, community health workers have been trained, and have in turn trained care givers on home based care in the area since 1997.

## **Chapter 2 LITERATURE REVIEW**

### **2.1 Overview**

Community home based care programmes have been advocated all over the world as a strategy to ease the growing pressure on hospitals. By definition it is the care of persons infected and affected by HIV/AIDS that is extended from the hospital or health facility to their homes through the family participation and community involvement within the available resources and in collaboration with health care workers (*NASCOP, Ministry of Health, 2000*). It is therefore a collaborative effort between the hospital, the family of the patient and the community. For it to be beneficial, home based care should be holistic so as to address clinical care, nutritional care, nursing care, social and spiritual care. On top of this the needs should be specific to the patient, the family and the community within which the patient lives (*WHO, 2000*). Experiences in Kenya and around the world show that AIDS is a chronic disease lasting months or years. The home is increasingly the option of choice for care for both sick individuals and health care systems. If the majority of people living with AIDS are to receive care within the family, a comprehensive range of medical, nursing, and counseling services must exist from hospital to home. The best care depends on a continuity of services, with referrals to help the sick receive comprehensive services as close to the home as possible. When care moves out of health care facilities into the family, community dynamics enter the picture.

## **2.2 Knowledge, skills and practice**

Research by UNDP in Sub Saharan Africa found fewer institutions operating in and delivering HIV/AIDS information, education and communication programmes (IEC), providing testing and counseling for HIV, and making condoms accessible in rural than in urban areas. Such services were both less accessible in remote communities and less tailored to the local realities (illiteracy, cultural practices, socio-cultural and gender differentiation, etc.). Thus, assumptions that knowledge of HIV/AIDS is in the range of 90% among the populations of several countries (Kenya, Uganda, Tanzania) is unlikely to be accurate insofar as rural men and women are concerned. More importantly, IEC, counseling and condoms alone are unlikely to have an impact in poor, remote areas where survival is the overriding concern and young men and women may have little incentive to change their lifestyles and adopt "safe" behaviours. Responses to HIV in rural areas have largely been based on assumptions made from experience drawn from urban environments. Moreover, "risk behaviour" has not, for the most part, been defined from the perspective of local population sub-groups and that is why risk behaviour is practiced and with limited justification by those concerned (*UNDP publication, Harare, Zimbabwe 1989*).

According to the WHO study (*WHO Kenya, 2000*), Community health workers reported lack of knowledge in home based care in general and therefore a need for continued education. They reported a lack of knowledge about various treatments for opportunistic infections, and about specific nursing care and treatments for other chronic illnesses. The workers voiced dismay at their inability

to provide the kind of service they knew they should, even after training. They also acknowledged their inability to train family caregivers in basic health care practices. These health workers spoke of the need for continued education on health care matters and how best to counsel and support patients and families. In the same study health workers in the hospital also voiced concern that they did not know how to provide emotional support and counseling to individuals and families referred to health facilities. Therefore family members not only lacked education on the necessary knowledge and skills required to care for the patient at home, they were also deprived of much needed psychosocial support and counseling. The lack of knowledge on what to do and how to do it exacerbated the fears of caring for the sick and the dying at home. Exposure and handling of a naked body by members of the community was treated with skepticism and fear. In another study done in Ethiopia on home care for PLWAs and attitudes, *Berhane et al, 1995* found out that Knowledge about AIDS was very high, with misconceptions about the disease being observed in some participants. It was noted that 55% of the respondents expressed willingness to give home-care for persons with AIDS. On the other hand, the majority (90%) regarded hospitals as the best place to give care for persons with AIDS. Most obstacles for not providing home-care for persons with AIDS were related to fear and misconceptions associated with the disease. In a related study in Kenya, it was also noted that sending the patients to the hospital for care was considered the norm and respected. The hospital was viewed as the institution that knew best about what to do with an ill or dying patient (*Makokha et al 1989*).

### **2.3 Attitude, stigma and community support**

People living with AIDS, and sometimes the families caring for them, may be rejected due to stigma. Without support, communities and families may abandon their traditional caring roles, and AIDS patients may be left homeless. In considering family care, the effect of HIV/AIDS on households is immense. Spending on care for AIDS patients may reduce the amount available for the health care of other family members (*Anderson et al, 1994*). Stigma, which is a social construction, dramatically affects the life experiences of PLWAs and their partners, family and friends.

Research by *Anderson et al, 1994*, showed that knowledge of HIV positive status makes an individual undergo affective expression of sadness, anxiety, anger, fear, shock, depression emotional and social withdrawal, feelings of shame, isolation, fatigue, as well as sleeping and eating disorders. HIV/AIDS is almost always accompanied by the belief that the sufferer is promiscuous or immoral. PLWAs find themselves being criminalized along with their families and socially ostracized. This has been fatal in terms of coping with HIV/AIDS. This is in line with findings from WHO publication done in Kenya, in 2000, where key informants and caregivers identified the challenges to include: being physically unable to provide personal care to the sick family members, feeling exhausted and overwhelmed, experiencing abuse, stigma and isolation, living in poverty, neglecting their own health, and being ignorant in the provision of care and accessing resources.



By alienating the affected and infected, HIV/AIDS patients feel they have nothing to gain by protecting themselves and others from infection which in turn breeds helplessness, complacency, indifference and vindictiveness, a perfect condition for the spread of HIV/AIDS. The caregivers themselves suffer abuse from the patients, cross-infections due to lack of precautions, emotional stress and are in most cases, ill prepared for the role. Apart from lacking transport, they lack choice and suffer high burnout. They face challenges like poverty, fear of contracting HIV, stigma and patient quality care issues like indiscriminate disposal of medical waste in home setting. They desperately need support to be able to share the burden with others who can understand and empathize with their predicament (*Excerpts from the 1<sup>st</sup> SADC Conference from 5<sup>th</sup>-&<sup>h</sup> March 2001, Gaborone, Botswana on Community Home based Care for HIV/AIDS patients*).

The lessons learned according to the reports from the 1<sup>st</sup> SADC conference included the need to access more training for those providing care; support and supervision, to disperse the emotional burden of caring, recognition of work and value of caring, and to improve clinical understanding; attention to staff welfare; management to take responsibility in improving staff welfare, to ensure responsibilities, open communication, inclusion in decision making and ownership.

In related findings, in HIV/Aids conference in Paris, 1999, individual carers were noted to undergo intense stresses while working in such conditions as slums in which volunteers were an indispensable support to the staff. The fear of getting

diseases is addressed through immunizations and protective training. The logistics of working over large distances with poor infrastructure and less resources adds to the burden, and care-givers were encouraged to recognize their status of over-involvement and to maintain a positive attitude- but this must also be affirmed through team leadership they work with (*Excerpts from the conference proceedings held in Paris in 1999 on Community care for people living with AIDS*).

In a socio cultural research carried out in Western Kenya, it was found out that 90% of the respondents were in polygamous relationships, where wife inheritance was common as was the practice of sending the wives back to their home when sick, there by relegating responsibility on the part on the husband (*Makokha et al 1989*). The report further says that the high prevalence of fear, stigma, and shame associated with HIV/AIDS were prohibiting factors for caring for the sick at home. The research highlighted that, although home based care is being seen as the magic solution from the outside, but without due consideration of the softer issues of socio-cultural norms, it may not succeed (*Makokha et al 1989*). In a similar study in Botwana on experiences of older women and young girls on home based care, *Lindsey et al, 2003* noted that older women reported feeling overwhelmed with the magnitude and multiplicity of tasks they had to perform. The women reported feeling exhausted, malnourished, depressed, and often neglectful of their own health. The young girls, reportedly often missed school and were sexually and physically abused, sexually exploited, and depressed. In addition, these caregivers experienced poverty, social isolation,

stigma, psychological distress, and a lack of basic caregiving education. In a similar study carried out in Togo, West Africa, *Moore et al, 2003*, found out that people with HIV/AIDS faced socio-economic, emotional and psychological battles as they attempt to deal with their physical health and the social reactions to such a stigmatizing disease. Thus, in order to contain the spread of HIV/AIDS, people living with HIV/AIDS, family caregivers, traditional healers as well as the public must be educated about the importance of preventing the disease and how each group can help achieve success in its control. As a way forward he noted that interventions in prevention and care should be designed with an awareness of these structural factors that contribute to the spread of AIDS and compromise the quality of care given to those who become infected.

In a study carried out in Kisumu (*Ayieko, M. A. 1989*), a number of children expressed their concerns about education. When orphans in this study were asked to discuss how they related to classmates and teachers at school, they narrated incidents of embarrassment and fear at being stigmatized as AIDS orphans. One pupil expressed fear of attending classes because he may be bewitched and die like his deceased educated parents. When asked to explain further, he discussed his beliefs on how his parents were bewitched because they were well educated and envied by their extended family line. Others stayed away from school due to lack of parental guidance and encouragement (*Ayieko, M. A. 1989*).

In a related study by WHO (*WHO, Kenya, 2000*), it was found out that if the family member was thought to have HIV/AIDS, the caregiver was often shunned

by neighbors and friends. There was a belief that the family was cursed or bewitched, and the caregiver was discriminated and stigmatized against. This experience leads to a sense of isolation and loneliness and in many cases, the caregiver did not know where to turn for support. In another study carried out in five countries, namely: Dominican Republic, India, Mexico, Tanzania and Thailand on Home help - "How communities cope with HIV/AIDS in 1993-4", it was found out that, household and community responses depend strongly on the perceived culpability of the infected individuals. It is generally thought more stigmatizing and shameful for women to have HIV/AIDS (*Aggleton et al, 1997*)

The study further found out that if a major wage earner died, financial problems caused as much stress for household as the stigma and physical symptoms associated with HIV/AIDS. A family will therefore conceal a members HIV status to avoid discrimination and stigmatization. Conversely, when some one falls ill, HIV infection is often wrongly suspected. HIV positive women were found not to receive the same level of care as men, and at the same time received little support in caring for the infected relatives because they usually hesitated to ask for help.

Children's nutrition and education was found to suffer in households with persons living with HIV/AIDS, although bereaved children received some support on short term basis from relatives. Although the main routes of HIV/AIDS transmission were understood, some anxiety existed about the risk of infection through air, bodily contact and sharing of needles (*Aggleton et al, 1997*).

## **2.4 Socio- economic impact on home based care**

Caring for a sick family member at home also creates poverty due to the costs of health care, drugs, medical supplies, and transportation have to be borne by the family (*WHO, Kenya, 2000*). As a consequence, families use whatever little financial resources they have on caring for their ill family members. In some instances, the sick person is often the family income earner. Therefore, families became increasingly poor as they tried to provide adequate care to sick family members at home (*WHO, Kenya, 2000*).

The impact of HIV on poverty is significant, because it touches on all aspects of development, and compromising all other measures intended to reduce poverty. In addition to escalating health care expenditures for both the government and families, the disease has created growing numbers of AIDS orphans. It reduces the size and experience of the labour force, with negative economic impact for households, due to the fact that it strikes mainly people in their most productive years. Several studies have shown how effectively HIV/AIDS can drive households into poverty when their assets (e.g. livestock) are sold to cover the costs of medical care, or when the available labour force becomes insufficient to tend to the necessary agricultural activities (*Food and Agricultural Organisation, 2000*).

In another research on Home based care, *Hansen et al* evaluated four home-based care programmes in Zimbabwe (two urban and two rural). He estimated the cost incurred per household in caring for bed ridden HIV/AIDS patients for three months. It was found to be US\$ 68-103 per household per month. The

time burden on carers was estimated to impose the highest cost on the household. Carers were found to be providing an average of 2.5 to 3.5 hours per day. This time was therefore not available for food production, business activities or employment. Income is therefore lost due to morbidity of the patients and reduced income to care giver. The resultant effect was to sell assets for the illness at the expense of education for the children (*Hansen et al 2003*).

Research done by WHO noted that actual capacity of communities to participate in defining and implementing home based care programmes has been limited by resource constraints, entrenched professional, social hierarchies, and public health models focused on individual behaviours and curative biomedical interventions. Gender and class discrimination also play a role (*WHO, Kenya, 2000*).

The government of Kenya has adopted a programme of retrenchment to address some of the financial problems facing the country. This is particularly true for government employees, however, retrenchment has also affected the private sector. At present, Kenya has an unemployment rate of 52% and as a result, there are many instances where families are living in absolute poverty and this impacts negatively on home based care for PLWAs.

## **2.5 Description of REEP'S home based care programme in Busia**

Rural Education and Economic Enhancement Programme (REEP) is a community based organization implementing a home based care programme in Butula Division since 1997.

It's mission is to improve the quality of life for the marginalized groups in rural communities in Western Kenya.

Before REEP began the programme, a baseline survey was carried out, which yielded the following results (*REEP baseline report, 1996*):

- Knowledge on HIV/Aids and Home-based care was 30%.
- Attitude towards HIV/Aids infected and affected individuals and families was negative with stigmatization and ostracisation.
- The practices in terms of nutrition supplementation, nursing care, psychosocial/spiritual counseling and client referral system were poor, inadequate and limited.

Targeted beneficiaries were:

- People Living with HIV/AIDS
- Orphans
- Women/Widows
- The elderly, especially those supporting orphans.

Objectives of home based care programme by REEP in Butula Division were:

- To facilitate the continuity of nursing care to the patients at home through community health workers and caregivers.
- To empower the family and the community with right knowledge thereby reducing stigmatization and ensuring long term care.
- To streamline the patient/client referral from the health institutions into the community and vice versa there by increasing access to medication

- To improve the nutrition status of the People living with HIV/AIDS and their families

### **Programme implementation**

The strategy of the programme was information, education and communication using trained volunteer community health workers selected from the communities with the help of community elders and chiefs. The community health workers were trained by certified trainers of trainers (TOTs) using the curriculum for training community health workers to care for persons with HIV/Aids at home. A total of 250 community health workers were initially trained by Pathfinder International and each member was expected to visit 5-10 families to train care givers, do home nursing, and basic counseling. Upon completion of the training, each community health worker was issued with a home based care kit that is replenished after every three months. At the end of five years this information, education and communication programme was meant to enhance ownership and acceptance of home based care at community level. This was to be achieved through increased knowledge on HIV, reduced stigma towards people living with HIV/Aids (PLWAs) and improved home based care support practices for PLWAs.

The results achieved by the REEP at the time of the study (2002-2005) according to their three year report (*Makohka et al, 2002*) were as follows:

- Food Distribution with World Food Programme for the infected and affected people in all sub locations (dietary supplementation)
- Construction of 200 houses for the elderly living with orphans (support).



- Income generating activities for 15 widows and orphans groups (resource mobilization)
- Running a VCT center in collaboration with Butula Mission Hospital
- Visiting of the infected and affected families, and offering nursing and spiritual care (social support).
- Supporting 100 orphans in schools by paying school fees and buying uniform (material support).
- Information dissemination through resource center at Butula (Knowledge).

The observed outcomes of the programme according to their three year report (*Makohka et al, 2002*) were:

- a) REEP has managed to reduce stigma associated with HIV/AIDS in Butula division and HIV/AIDS is now accepted as a problem that can affect anyone in the community. The people of Butula division have proven that anyone can get AIDS because they have witnessed REEP counselors disclose AIDS associated deaths even among religious leaders. REEP has initiated nine support groups or people living with AIDS in Butula division of Busia district. All the group members have undergone VCT. Among them, over 134 have gone public about their status. At first, only women joined support groups but according to the report there were also male participants in the groups. One of the support groups-Bulwani branch have set up a dairy project which is sponsored by the Firelight Foundation and UNDP-Africa 2000 Network. Before the community had feared even moving near the body of someone who had died of AIDS, but according to

the report, this had changed and families now sought to know how to handle the bodies of those who die of AIDS.

- b) Openness and disclosure of HIV/AIDS-AIDS and deaths had increased and people talked openly about the disease than before the inception of the programme. According to the report, this had greatly helped reduce the spread of HIV/AIDS through wife/husband inheritance.
- c) Due to the high mobilization of Butula division and the quality of home based care services, Butula has one of the busiest VCT site in the district with an average monthly attendance of 150 clients, according to the report.

The constraints faced by REEP after three year intervention were listed in the report as follows:

1. Lack of transport was a major logistical hindrance since the organization is operating in a large area with only six bicycles. Many times the CHWs have to walk from patient to patient to provide home based care. In most cases, reaching when they are already exhausted.
2. Poverty is a major issue and a reality in Butula division. Lack of basic necessities like food, shelter, clothing and medicines have remained big challenges to provision of home based care.
3. Low resource base is also an issue. REEP can't pay the CHWs for the time lost in home based care and refresher trainings. This has led to high turnover of community health workers (50 CHWs had dropped out by time of the study).

### **Chapter 3 RESEARCH PROBLEM AND JUSTIFICATION**

The number of people falling ill as a result of HIV infection will rise dramatically in coming years, regardless of existing prevention efforts. Since AIDS is a chronic disease lasting months or years, the home is increasingly the option of choice for care for both sick individuals and health care systems. If the majority of people living with AIDS are to receive care within the family, a comprehensive range of medical, nursing, and counseling services must exist from hospital to home. The best care depends on a continuity of services, with referrals to help the sick receive comprehensive services as close to the home as possible.

Home based care is therefore being viewed both internationally and nationally as the way forward for the AIDS infected persons, because the cost of taking care of the patients in the hospitals is rising and the hospitals have limited capacity to deal with other illnesses like malaria that are still far from being controlled and are still claiming lives. This is due to the fact that the social sectors including health in Kenya are experiencing low budgetary allocation due to Structural Adjustment Programmes (SAPs), rapid population growth rate among other factors (Kenya Economic Survey 2003). For instance, the per capita expenditure on health has reached an all time low of US\$. 3.8 (*The Kenya National Development plan 2002 -2006*).

The National AIDS Control Council in its draft strategic plan (April 2000) has continuum of care and support at home as one of its strategies in reducing hospital admission for HIV/Aids related illnesses. However, the government is yet to start implementation of home based care even in one province to

experience the successes or failures associated with the program. The NGO/CBOs that are currently involved in the implementation of home-based care are donor driven and are supposed to hand over the activities to the communities after a specified period of funding, and this can still be shortened when donor funds run dry for various reasons. Given the prevailing challenges like cultural beliefs, high illiteracy levels, stigmatization, poverty and low socio economic status in rural Kenya, are communities having the knowledge, skills and competence to increase home based care uptake and sustain it? Despite the increasing number of the people being infected by HIV in Kenya, many prevention and control programmes by the government have paid more attention to prevention, voluntary counseling and testing and provision of antiretrovirals to the infected while ignoring nursing care and nutritional support at home. In Busia District where REEP (Rural Education and Economic Enhancement Programme) is implementing home based care activities, the strategy employed has been increasing knowledge of care givers through information, education and communication by trained volunteer community health workers. While most care givers are blood relatives and family members of the infected person, it is being assumed that, they have adequate knowledge, skills, positive attitude, time and resources for food, medication, shelter, clothing and beddings that are prerequisite for quality home based care and support at home. Has this home based care programme by REEP influenced the knowledge, skills and competence of the caregivers? New and innovative approaches are therefore

needed to care for HIV/Aids patients at home to free bed space in public hospitals to cater for other diseases.

Despite, not having started implementation of home based care, the government has not even assessed knowledge, skills, and competence resulting from on going home based care programmes initiated by NGO/CBOs. The purpose of this study was to determine the community utilisation of on going home based care programme through assessing respondents' knowledge, attitudes and practices in Butula Division, Busia District.

### **3.1 Main Objective**

The main objective is to determine community utilisation of home based care programme through assessment of the knowledge, attitudes and practices among the communities in Butula Division, Busia District.

### **3.2 Specific Objectives**

- 1: To determine the socio-demographic factors of communities in Butula division that influence home based care knowledge, attitudes and practices.
- 2: To establish the knowledge and skills among community members in delivering home based care.
- 3: To determine community support towards the home based care.

### **3.3 Hypothesis**

An information and education programme by REEP has increased people's knowledge about home based care.

## Chapter 4 METHODOLOGY

### 4.1 Study Location

Busia District, where the study was conducted, is one of the six districts that form Western Province and has a population 405, 389 people with density of 321 persons per sq. km. The population is projected to increase to 485, 047 people with density of 385 persons per sq. km in 2010. The district borders the Republic of Uganda to the west, Teso and Kakamega districts to the North, Butere-Mumias to the East, Siaya and Lake Victoria to the South (*Busia district development plan 2002-2008*). The district has HIV/AIDS prevalence rate of 14.2%, compared to the national figure of 7.3% (*NASCOP, 2005*).

Strategically, Busia borders the republic of Uganda, which was one of the first countries to face the brunt of HIV/AIDS pandemic with very high prevalence rates during the peak times (45% in the late 1980s to early 1990s). This has contributed to the widespread HIV/AIDS infection, due to cross border interactions. Secondly it is the resting place for the truck drivers coming all the way from Congo, Rwanda, Uganda and Southern Sudan. It is also a border town on the main highway connecting the hinterland of the French speaking central Africa to Nairobi and Mombassa. These countries have some of the highest prevalence of HIV/AIDS in the region. Thirdly, Busia also borders Nyanza province which is the most affected by HIV/AIDS with an estimated 30% of national burden (*NASCOP, 2005*).

## **4.2 Study population**

### ***4.2.1 Socio cultural systems in Busia District***

The communities in Busia District are rural dwellers with subsistence agriculture as the main economic activity. Socially, the people of Busia are polygamous, with strong family ties among the clans. However, frequent deaths are weakening the extended family support system and threatening to separate household members. It is likely to continue reducing surviving members' capacity to manage and support each other until an effective educational programme is established.

The growing individualistic trend could also be attributed to the frequent droughts, famine and civil unrest that have weakened and undermined many other societies. The current urban lifestyle and tendency to emulate the Western nuclear family are also playing a role in eroding the concept of extended family support system in Busia. Funeral rituals and expenses which were once an affair of the whole community are becoming a household burden. Children are no longer the collective responsibility of communities, a legacy that has been historically associated with child rearing in Africa. Extended families no longer feel obliged to welcome orphans when they are not even sure of the future for their own children. This is due to the over stretched household resources and the discouraging number of deaths in communities from HIV/AIDS. Communities in Busia have been known for their spirit of support. Family and friends would unite in pooling resources together to help each other during major financial needs. Such devotion and attachment are slowly fading away as each family fends for its own survival (*Busia District Development Plan 1997- 2001*).

The people speak mostly Luhya language (a dialect of Bantu) and live mostly in grass thatched home stead.

#### **4.2.2 Food security in Busia district**

The climate supports two cropping seasons during the year round. During the long rains, crops such as maize, sorghum, sweet potatoes, soya beans, cowpeas, green grams, beans and onions are grown in most parts of the district. They practice mixed farming by keeping a few heads of livestock and cultivating crops on a small scale due to high population density, and limited workforce at the family level, contributed by various factors, among them HIV/Aids. Some families have sugarcane as a cash crop that matures after three years when the family is highly indebted.

Some families do not own adequate land for agricultural production, and during the terminal stages of the illness, many households sell off the little land to raise money for hospital bills and medication. Some hospitals and clinics also encourage terminally ill patients to surrender land title deeds as security for medical bills. This happens with full knowledge of the medical personnel that the patients will not recover fully to claim back the documents. This makes certain households lose a lot of land to such medical institutions. Furthermore, property such as land is sold off in a desperate bid to raise money for medication and other essentials to support families when parents are ailing. By the time both parents are dead, families are left with limited land and property. The situation is even made worse in cases where the ancestral land has not been subdivided amongst the sons. The grandparents (in particular the grandmothers), in an effort



to save her dying sons or daughters-in-law, sell possession to raise money for medication. Such activities deprive households of the essential means for sustainable livelihood in rural areas (*Busia District Development Plan 1997 - 2001*).

These factors have contributed to poverty, food insecurity and malnutrition, that further fuel the spread of HIV/Aids.

#### **4.2.3 Education situation in Busia District**

School enrollment and retention are still low while youth unemployment rate is high and this creates a pool of youths who are idle thus engaging in unprotected sex. The girl child education, although picking up, it is still frowned upon as a non-issue and this is reflected in early marriages of the girls and low literacy (males 76% and females 55.3%) levels in the District (*Busia District development plan, 2002-2008*). The village polytechnics to absorb the youth for skills training are operating at the bare minimum and worsening the unemployment situation further. This has contributed to Busia district being ranked among the poorest districts in Kenya with a poverty index of 57 % (66% of the people live below poverty line) compared to the national level of 43% (*A popular version of the first poverty report in Kenya; June 1999*).

#### **4.2.4 Health situation in Busia District**

Major diseases in the district are malaria, acute respiratory infections, anaemia and intestinal worms. Malaria alone contributes to about 50% of the total morbidity in the district. Most of the mortality is felt in the infants (IMR of 86/1,000

compared to National 77/1000) and pregnant mothers (MMR of 460/100,000 live births compared to national figure of 414/100,000). Malnutrition (stunting) is quite rampant in this District peaking at 42 % compared to the national level of 31% (*Busia District Development plan, 1997-2001, MOH, 2006 and KDHS 2003*). Malnutrition is common among children of 0-5 years of age and breast-feeding mothers. The causes for the high level of malnutrition in the district include large families coupled with general poverty, over-reliance on starchy foodstuffs and food insecurity. Some of the noticeable effects of low level of nutrition in the district are constant increase in morbidity, mortality and faltering growth (*Busia District Development plan 1997-2001*)

HIV/AIDS has had its toll on the district with a prevalence rate of 14.2% compared to the national figure of 7.3% (*NASCOP, 2005*). This has resulted in increased number of widows and orphans. In some circumstances, the houses are headed by children and this has disadvantaged the girl child who has to take care of the other children or ailing parents thus forfeiting school in the process.

The health facilities in the district are barely coping with the HIV/AIDS problem, since most of them are under staffed with scarcity of medical equipment and medicines. With scarcity of protective attire, the health staff are always worried about being infected and as a result the nursing care is quite deplorable.

The total number of health facilities in the district are 28 out of which 2 are government hospitals, 5 private nursing homes, 7 health centers, 10 dispensaries and 4 mission hospitals. The distribution of the health facilities per division are as shown in Table 1.

**Table 1 Distribution of health facilities in Busia District**

Location	Number of health facilities
Hutuia	4 (3 health centers and 1 dispensary)
MocJaiangi	4 (1 hospital, 1 health center, 2 dispensaries)
Fuoyula	8 (1 hospital, 1 health center, 6 dispensaries)
Nambale/matayoys	7(3 health centers, 3 dispensaries, 1 hospital)
Township	5 (1 hospital and 4 private nursing homes)

There are 8 doctors and 396 paramedical staff operating in these 28 health facilities in the district, and the doctor population ratio is 1:41,200 compared to a national figure of 1:10,000 (*Busia District Development plan, 1997-2001, 2002-2005*). In 2002, HIV related admissions in Busia District hospital were 253 with 104 deaths (case fatality rate 24.5%) while in 2003, HIV/Aids related admissions were 289 people and out of this 84 died (case fatality rate 29.4%). During 2004, admissions stood at 372 with 104 deaths (case fatality rate 28%). For those who underwent counseling and testing when it started in 2004, 13,124 were tested in the district hospital and 4179 (31.8%) were positive for HIV antibodies. In 2005, 4548 were tested and 4548 (31.3%) were positive for HIV antibodies. The percentage of HIV/Aids admissions at Busia district hospital is estimated at 50-60% of total admissions (*Busia Hospital statistics, 2002, 2003, 2004, 2005*).

### **4.3 Study subjects.**

The study subjects comprised a sample population of community members, among them, people living with AIDS, the caregivers, community health workers, orphans, widows and other community members. In addition, key informants included community health workers, community leaders, chiefs, Divisional officer, District Medical Officer and staff of REEP.

#### ***4.3.1 Inclusion and exclusion criteria***

Respondents between 15 years and 65 years residing in the villages where REEP activities are implemented were included. Excluded were those below 15 years, above 65 years and those visiting (less than three months) during the time of interview.

### **4.4 Study design**

This was a descriptive cross sectional study using structured interviews, focus group discussions and key informant interview guides that provided insights into the knowledge, attitudes and practices on home based care programme implemented by Rural Education and Economic enhancement Programme (REEP) in Butula Division.

## **4.5 Selection of participants**

### **4.5.1 Sampling methods for quantitative data.**

The targeted population was 15 to 65 years age group in Butula division. This population was purposely sampled since REEP implements the home based care programme in this division. A list of all the villages (200) in the division was made on a sampling frame. This was followed by cluster sampling of villages, where the eligible respondents was interviewed. The average number of households in the village was found to be 20 and this represented the number of respondents per chosen village to be interviewed. Since the number of respondents required was approximately 400, the study required at least 20 villages. The sampling interval that gave 20 villages out of 200 listed was 10. Every 10<sup>th</sup> village was systematically selected from the list of 200 and the eligible respondents (heads of households between 15 and 65 years) interviewed.

### **4.5.2 Sample size**

The sample size was determined using the following formula:  $n = Z^2 pq / d^2$  (Wayne W Daniel 1998), where: **n** =desired sample size.

**Z**= the standard normal deviate that corresponds to 95% confidence interval, set at **1.96**

**p**=.the proportion in the target population of Butula Division that have adequate knowledge on home based care (estimated at 50%).

**q**= 1-P

**d**. =. The degree of accuracy desired in this study, which is set at **.05**

Therefore the estimated sample size is **n. = 384**

#### **4.5.3 Selection of participants for qualitative data.**

The respondents for in depth interviews were chosen from the local authorities, people living with AIDS, caregivers, Constituency Aids Control Committees (CACCS), community health workers and staff of REEP in Butula division. The respondents represented as much as possible the villages where REEP operates and same applied for the focus group discussions. To ensure representation, all the stakeholder groups were approached by Principle investigator to select participants for the in depth interviews and focus group discussions.

#### **4.6 Data Collection**

Structured questionnaire was used to collect quantitative data while checklists and discussion guidelines were used in qualitative data collection. . (**Annexes I, II and III**).

##### **4.6.1 Structured interviews**

The structured questionnaires focused on the knowledge, perceptions, skills and practices of care giving of ill family members at home. The questionnaires were first pre-tested and administered by trained interviewers, fluent in Luhya language who were selected from the members of the community in Butula Division, Busia District. The family members were interviewed in their local language and responses recorded in English. Eligible respondents included the members of the community, People Living with AIDS (PLWAs), care givers and community health workers.

#### **4.6.2 Focus Group Discussions**

Same sex focus group discussions were conducted with a total of about 50 participants in groups of 10 members (2 male and 3 female groups). The participants were drawn from people living with AIDS (PLWAs), widows, care givers, local authorities and community members. Trained same sex moderators facilitated the discussions. The questions asked and answers were recorded to help illuminate and support some of the findings in the quantitative data. The language used was Luhya and the moderators chosen were fluent in it.

The questions and information recorded were in English, but tapes were in local (Luhya) language. After each session, the research assistants and principle researcher translated, transcribed and compared information recorded to achieve themes and views presented in the discussion.

#### **4.6.3 In Depth Interviews**

Twenty (20) in depth interviews with representation from majority of the stakeholders were carried out. The DMO was interviewed on the ministry's activities to alleviate the impact of HIV/AIDS in the District, and what he thought was merits and demerits of the home based care programme in the district. REEP staff were interviewed on what their organizations had contributed in increasing knowledge, reducing stigma and increasing community uptake.

In the list of interviewees were District officer (DO), opinion leaders, chiefs, local counselors, caregivers, PLWAs and patients from the division admitted in the sub-district hospital within the division (Khunyangu) with HIV/AIDS related illness.

The patients were identified with the help of the clinical officer in charge (for diagnosis) and locations where they live from the patient records.

An effort was made to talk to every person or organization involved in any aspect of PLWAs care in the community. It was necessary to have all such individuals involved because their support for interventions would be crucial.

#### **4.7 Variables**

##### **4.7.1 Independent variables**

Socio demographic characteristics (Age, Sex, Religion, Socio-economic Status, marital status and level of education)

##### **4.7.2 Depended variables**

- Knowledge on Home based care.
- Attitude towards on home based care
- Practice of home based care

#### **4.8 Data Analysis and processing**

##### **4.8.1 Qualitative Data**

Each focus group discussion session was taped and notes taken. Immediately after the session, the facilitator and principal investigator translated and transcribed the tapes to achieve accurate representation of what was discussed. Comparative analysis of the transcripts and the recorded notes was conducted when all the five sessions were completed. The principle investigator then



analyzed views of different groups to establish which views were held by the participants. The information from in-depth interviews was recorded in the interview sheets and analyzed for themes held on various issues by the participants.

#### **4.8.2 Quantitative Data**

As for the structured interviews, the information was gathered, cleaned and analyzed by Epi info software programme by a statistical officer together with the principle researcher. Relationships between independent and dependent variables was analyzed using chi square while logistic regression was used to eliminate confounding factors between the variables. A scoring method was also used to assess the respondent's knowledge, attitude and practice. The results were presented in figures ranging from frequency tables, pie charts, line graphs and bar charts.

#### **4.9 Quality control and Research integrity**

Although the questionnaires were written in English, the research team which comes from the Luhya community was sensitive to issues of translation, observation and sharing knowledge about local customs and practices. The principle researcher interviewed some of the respondents and participated in all the focus group discussions. Regular research team meetings were also held throughout the study to discuss and clarify issues related to data collection and contextual understanding of traditions, culture and semantics.

The quality control was ensured by adequate training of the research assistants, pre-testing the questionnaires, assuring the respondents of the confidentiality of their information, adequate supervision during data collection and cleaning the data before entering in the computer.

#### **4.10 Ethical considerations**

The study was cleared by Department of Community Health, University of Nairobi, local authorities in Butula Division, District medical officer of Health in Busia District and the respondents were verbally informed about the study and the objectives for it. Consent was given verbally by each respondent for structured interviews and in groups for focus group discussions.

The confidentiality of the respondents and community members was kept and information collected used solely for intended purposes.

Those found sick in the community during the collection of data were referred for treatment to the nearest health facility.

#### **4.11 Limitations of the study**

- Morbidity and mortality patterns at the District hospital could not be used as indicators of community uptake/utilization of the programme because of stigmatization and other confounding factors.
- Getting a representative sample of HIV positive clients who are benefiting from home based care in the division was not feasible due to stigmatization and unavailability of VCT results.

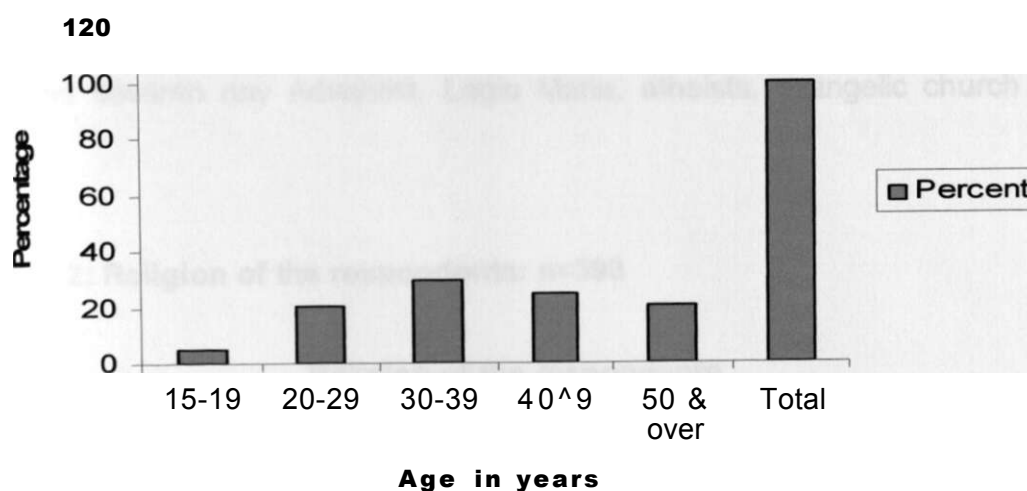
# Chapters RESULTS

## 5.1 Socio Demographic Characteristics

### Age

The ages of the respondents ranged from 15 to 65 years. The modal age group was 30-39 years with a mean age of 34.5 years. This age group had the highest percentage of respondents (29.6%) followed by 40-49 year age group at 24.7% while the age groups 20-29 and 50-65 have almost similar percentage as shown in Figure 1.

**Figure 1: Age of respondents in years and their Frequency: n=393**



### Sex

Most of the respondents as shown in Table 2 were females (68.2%) as opposed to males (31.8%).

**Table 2: Sex of the respondents: n=393**

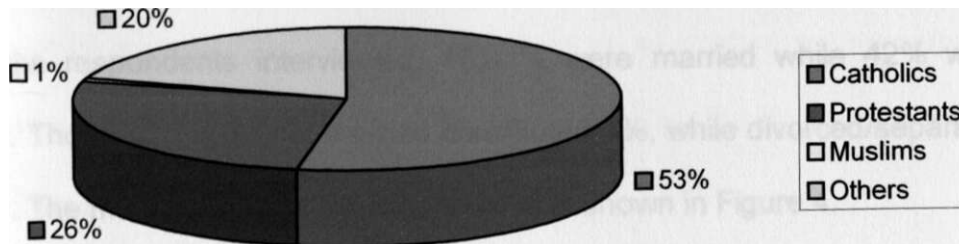
Sex	Frequency	Percentage
Male	125	31.8
Female	268	68.2
Totals	393	100

### Religion

Most of the respondents as shown in Figure 2 were Catholics (53%), protestants (26%), Muslims were 1%, while others contributed to 20%. The others category included seventh day Adventist, Legio Maria, atheists, evangelic church and Israel.

**Figure 2: Religion of the respondents: n=393**

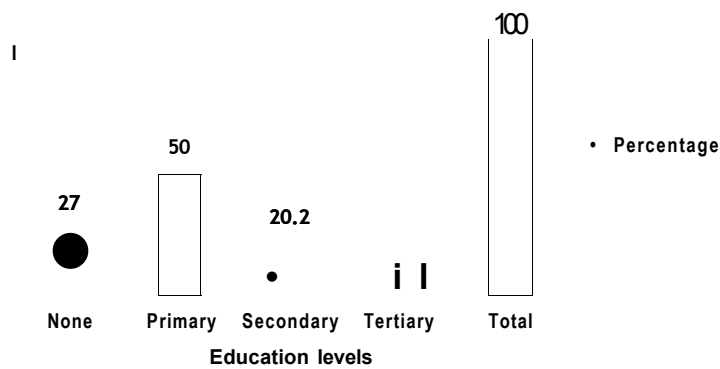
### Religion of the respondents



### Level of Education

One half of the respondents as shown in Figure 3, had primary level of education, while 27% had no formal education, 20.2% had secondary education and 2.8% had tertiary education.

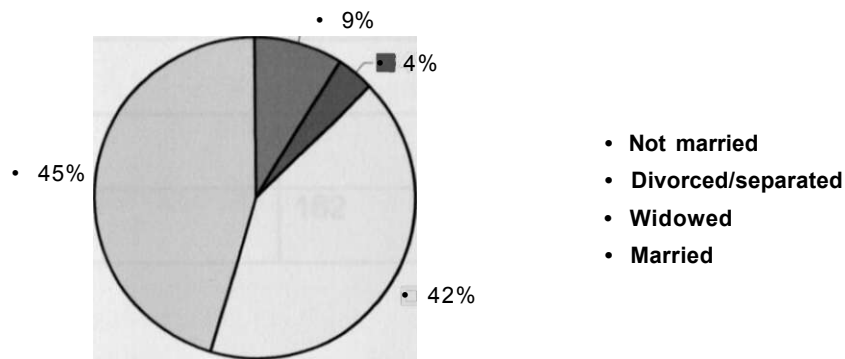
**Figure 3: Level of education of the respondents: n=393**



### Marital Status

Among the respondents interviewed, 45.0 % were married while 42% were widowed. Those who were not married constituted 9%, while divorced/separated were 4%. The marital status of the respondents is shown in Figure 4.

**Figure 4: Marital status of the respondents: n= 393**



### **Duration of Widowhood**

The majority of those widowed were within 1 to 4 years of widowhood (42%) as shown in Table 3. Those who had been widowed for less than one year were 21% while 5-9 years of widowhood were 20.4% and over 10 years of widowhood were 16.6%. From focus group discussions it was noted that HIV/AIDS is the highest contributor to widowhood in Butula Division, as pointed out by some of the widows who were care givers to their spouses under the home based care programme.

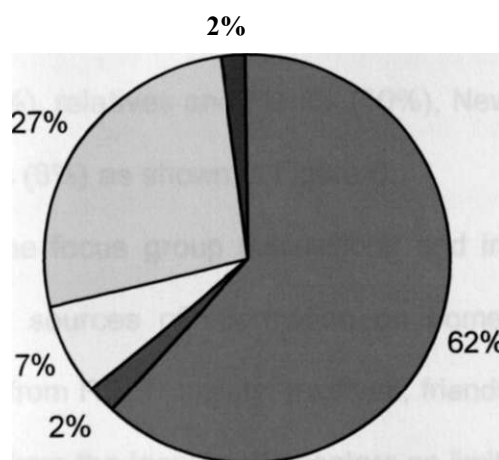
**Table 3: Duration of widowhood: n=162**

Duration in years	Frequency	Percentage
< 1	34	21.0
1-4	68	42.0
5-9	33	20.4
10 and over	27	16.6
Total	162	100

### Occupation

The majority (62%) of the respondents as shown in Figure 5 were unemployed, 27% are self-employed and casual workers constitute 7%. Student /pupils constituted 2% while CHW/counselor/home visitor were 2%.

**Figure 5: Occupation of the respondents, n=393**



- Unemployed 241
- Student/pupil 9
- Casual work 28
- Self employed 104
- CHW/counsellor/home visitor 7

## 5.2 Level of Knowledge on home based care

Most of the respondents (67.3%) had heard of home based care, while 32.7% had not as shown in Table 4. From the focus group discussions and in depth interviews, majority of the participants had heard of home based care.

**Table 4: Awareness of home based care programme by respondents:n= 392**

<b>Response</b>	<b>Frequency</b>	<b>Percentage</b>
Yes	264	67.3
No	128	32.7
Total	392	100

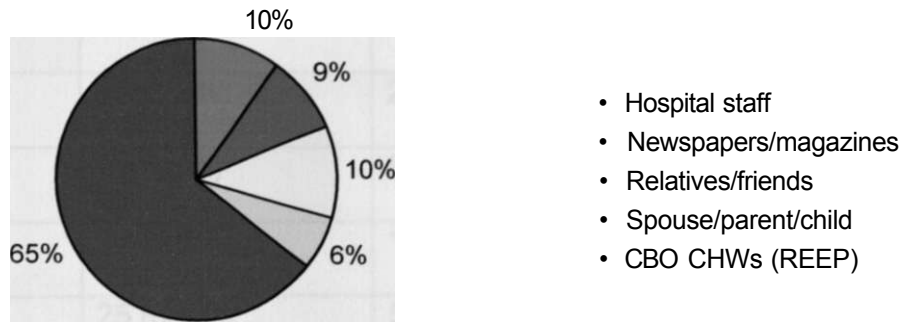
### **Sources of information regarding home based care**

The respondents identified the sources of information providers as community based organisations (65%), which was in form of training, government hospital staff (10%), relatives and friends (10%), Newspapers (9%) and immediate family members (6%) as shown in Figure 6.

During the focus group discussions and in depth interviews, the respondents identified sources of information on home based care as community health workers from REEP mainly: relatives, friends, newsletters and community health workers from the local health centers on limited extend.



**Figure 6:Source of information: n=130**



### **The institutions providing home based care in Butula Division**

The respondents identified the institutions providing home based care as REEP (66%), Government (31.6%), church organisations (15.1%) and international non-governmental organisations (2.1%) as shown in Table 5.

From focus group discussions and in depth interviews, it was noted that training and educating care givers on home based care in the Division, is done mainly by CHWs from REEP. The other institutions mentioned were the Catholic Church, Government (CHWs from the Government health units) and other NGOs (Pathfinder international).

**Table 5: Institutions providing home based care training: n =377**

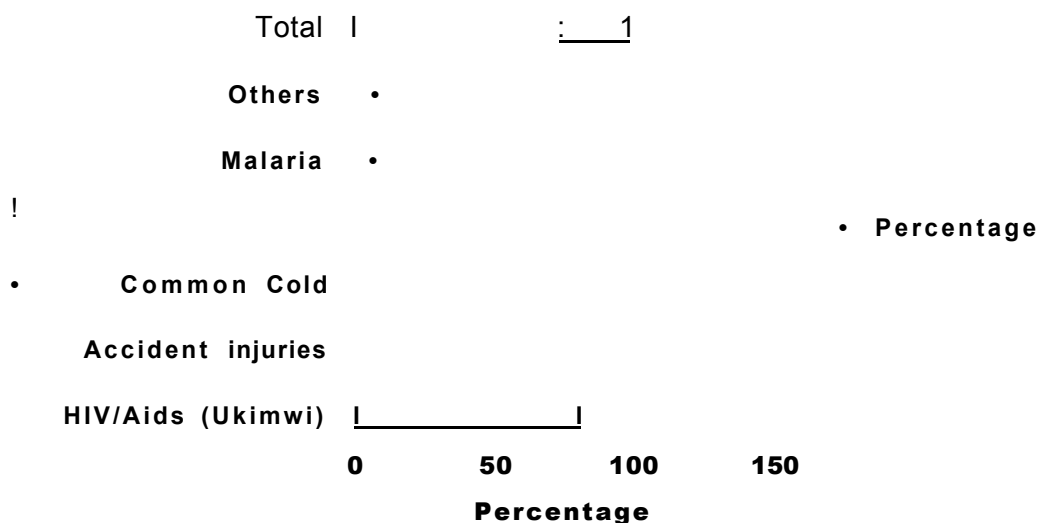
<b>HBC provider</b>	<b>Responses</b>		
	<b>Don't know</b>	<b>Yes</b>	<b>No</b>
NGO (REEP)	25 (6.6%)	249 (66%)	103 (27.4%)
NGO (others)	25(6.6%)	8(2.1%)	344 (91.3%)
Government	25 (6.6%)	119(31.6%)	233 (61.8%)
Church	25 (6.6%)	57(15.1%)	295 (78.2%)

### **Knowledge on disease managed by Home based care**

Most of the respondents (81%) as shown in Figure 7 identified Ukimwi (HIV/AIDS) as the disease requiring home based care. Other diseases identified by the respondents were malaria (7.9%), accident/injuries (1.3%) and common cold (0.8%). Tuberculosis, diarrhoea and typhoid were also listed under others and constituted 9.0%.

When participants were asked about the disease(s) that home based care manages during focus group discussions, majority of them cited "ukimwi" (HIV/AIDS) as the disease. Some of them mentioned other diseases such as malaria, tuberculosis and skin diseases, but went ahead to say that these diseases are common in Aids patients.

**Figure 7: Diseases managed by home based care: n=390**



**Knowledge on the existence of Home based care services in community**

Seventy six percent of the respondents confirmed that the HIV/AIDS clients in the community know about the existence of home-based care services provided by REEP. However, 17.5% did not think that the HIV/AIDS patients were aware about the existence of home based care services. Those who did not know about the home based care services were 6.4%. When asked if community members are educated about home based care, 62.4% said they were educated as opposed to 27.7% who said that they are not educated and 9.9% who didn't know.

### Knowledge on source of information for caregivers in the community

On how the caregivers and community is educated about home based care, community health workers were identified as the main source of information (75%) followed by mass campaigns by same CHWs (13%) and leaflets/pamphlets distributed by the same CHWs (12%) as shown in Figure 8.

During focus group discussions, the participants noted that CHWs from REEP have informed and educated the care givers in the community on home based care through seminars, workshops and mass campaigns. However the trainings are not frequent, so some CHWs forget what they were taught and therefore feel frustrated. Some of the participants were community health workers from REEP, and went further to explain how they inform and educate community members.

**Figure 8: Channels of community education on home based care: n=255**

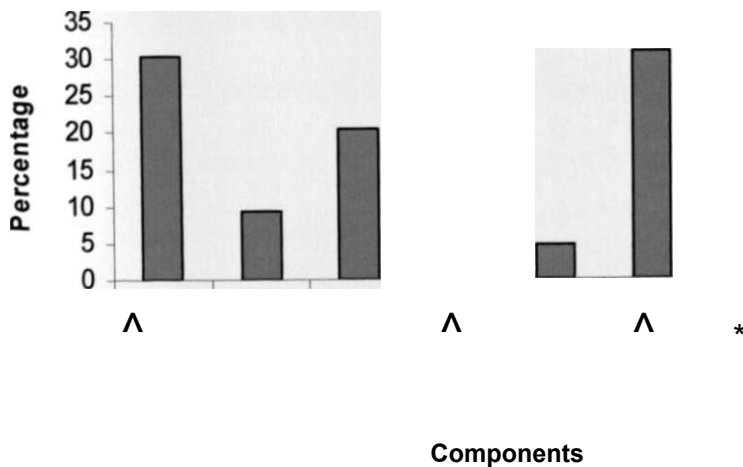


### Components of Home Based Care.

Out of 380 respondents 31.0% identified all components listed as, counselling, praying for the sick, good nutrition, treatment of opportunistic infections and nursing of the sick. However, 30.2% of the respondents said it was counselling while 20.4% attributed home based care to good nutrition, 9.3% to praying for the sick, 4.7% to nursing of the sick, 2.3% to treatment of opportunistic infections 0.3% to being there for them and 1.8% didn't know. The participants from focus group discussions enumerated the components of home based care as: spiritual and psychological counselling, nutritional support, nursing of the patients, treatment and provision of antiretrovirals.

When probed further on their knowledge on these components, most of them expounded that good nutrition meant giving PLWAs balanced diet comprising of proteins, fats, carbohydrates and vitamins, while nursing should be done with gloves.

**Fig. 9: Components of Home-based health care**



## **Knowledge on advantages of Home Based Care**

The advantages of home based care, as illustrated in Table 6, were identified as patient being nursed in familiar environment (40.7%), it being cheap (30.6%), good support from family members and relatives (14.4%) and patients handled with dignity (0.01%). The other benefits and advantages (14.3%) comprises of living longer than in hospital, nursing patient and doing other things, patient is visited any time as opposed to hospital where visiting is scheduled, easy access to patient needs and less worries. However, there are others who said that there are no benefits and if nursed at home, patients are hungry most of the time and therefore a bother to the care givers.

During focus group discussions and in depth interviews, majority of the participants preferred home based care due to the fact that patients are nursed in familiar environment as opposed to the hospital where referral and transport costs are high, especially when a patient dies in hospital. Some participants were of the view that disadvantages outweigh advantages given the nursing burden, food insecurity and poverty in the division.

**Table 6: Advantages/benefits of home based care: n=378**

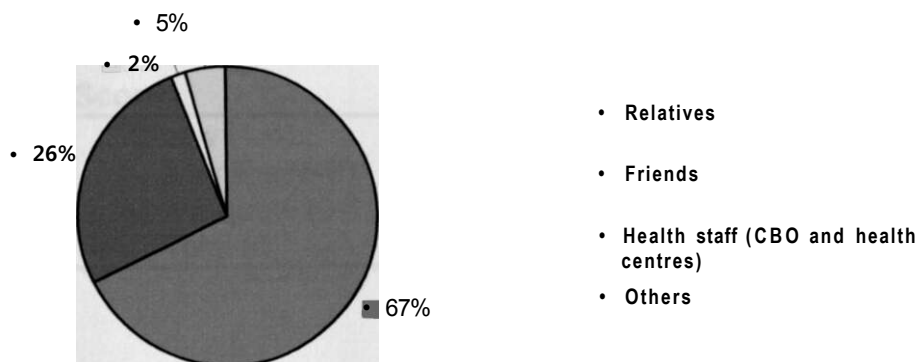
<b>Advantages/benefits of home based care</b>	<b>Frequency</b>	<b>Percentage</b>
Services are cheap/affordable	113	30.6
Patients nursed in familiar environment	154	40.7
Good support from family and relatives	54	14.4
Patients handled with dignity	3	0.01
Others	54	14.3
Total	378	100

### **Discussions and education on home based care in communities**

The persons with whom the respondents discussed home based care were mostly relatives (67.8%), friends (26.1%), health staff from the CBOs/NGOs and church (1.5%) and others (4.6%) as shown in Figure 10. The others comprise of women groups, care givers, fellow patients, neighbours, congregations in funerals and chiefs barazas.

Inter-personal communication and education was pointed out as the fastest way of passing information during the focus group discussions. This is usually done between peers and family members.

**Figure 10: Persons involved in home based care discussions: n=199**



### **5.2.1 Knowledge scores on home based care**

In order to find out level of knowledge for each individual responded, a scoring system was used and categorised into three groups; namely; low, average and adequate.

The scores ranged from 1 to 11 with mean score of 8 and standard deviation of 2.64. The median and the mode were 9 and 10 respectively. Those who score 1-4 had low knowledge, 5-8 had average knowledge and those who scored 9-11 had adequate knowledge on home based care as shown in Table 7. Those with low knowledge were 57 (14.5%), average were 132 (33.6%) while 204 (51.9%) had adequate knowledge as shown in Table 7. In order to test the hypothesis that the programme has increased the level of knowledge from the initial level of 30%, a standard normal deviate test was used leading to the rejection of the null hypothesis ( $z = 15.01, p < 0.05$ ).



**Table 7: Categorized Knowledge scores on home based care**

<b>Score</b>	<b>Frequency</b>	<b>Percent</b>
Low (1-4)	57	14.5
Average (5-8)	132	33.6
Adequate (9-11)	204	51.9
Total (n)	393	100.0

### **5.3 Skills and practices**

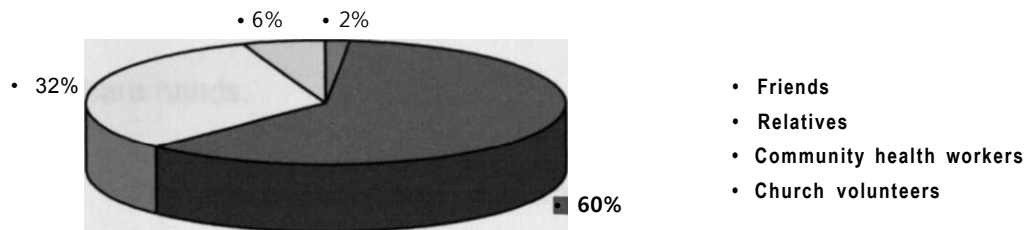
#### **Nursing and Counselling Care Skills**

Sixty percent of the respondents confirmed that this is done by relatives, while 32% said that it is done by community health workers, 6% attributed the care to church volunteers and 2% said that friends do the nursing as shown in Figure 11.

In the Luhya setting, nursing and counselling are mostly done by the mothers and this was confirmed by 37.3% of the respondents, while 35.3% said that nursing and counselling are done by wife followed by 14.9% for daughter, 10.9% for sister, 0.8% for husband, 0.4% for son and 0.4% for brother.

In order to understand the amount of quality time spend nursing and counselling PLWAs, respondents gave the times as; when time allows (66.6%), once in two days (13.8%), 1-2 times per day (12.8%) and more than two times per day (6.8%).

**Figure 11: Persons nursing PLWAs: n=381**



### **Protective Nursing Care Skills**

Majority of the respondents (75%) confirmed that nursing is practiced using gloves and/or protective clothing, while 18% said that nursing is done with bare hands, 4% were using nylon papers and 3% paper bags (Figure 12).

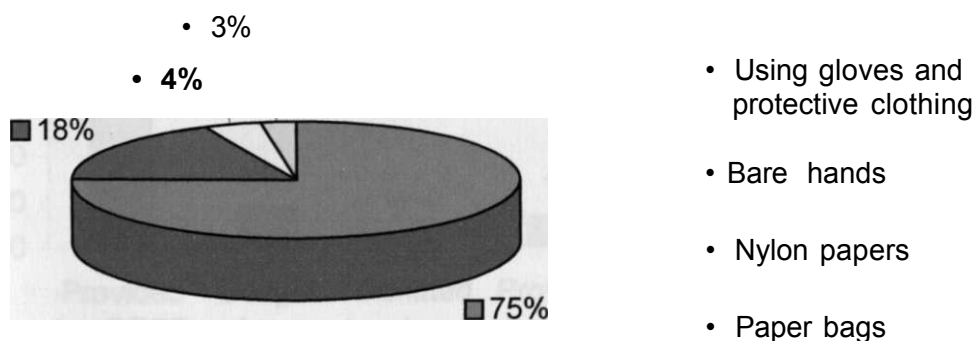
Most of the respondents (91.9%) pointed out that protective nursing was practiced to prevent HIV infection to care givers while 8.1% thought that this was to prevent the care givers from re infecting the patients.

For those respondents who said that people are using bare hands to nurse the patients had the following reasons; gloves are not available because they are not affordable (61%), patients think carer is inhuman (11%), relatives/carer think that nursing their kin with gloves is inhuman (4%) and 24% had other reasons that included, lack of correct information and ignorance.

Participants from focus group discussions noted that care givers can be infected by/re-infect the patients they are taking care of, if the nursing is done without

gloves/protective clothing. Nursing of patients with gloves was practiced when home based care kits containing them were supplied or replenished by REEP. Otherwise, when care givers run short of gloves, they use paper bags, nylon papers and bare hands.

**Figure 12: Practice of nursing PLWAs: n=381**



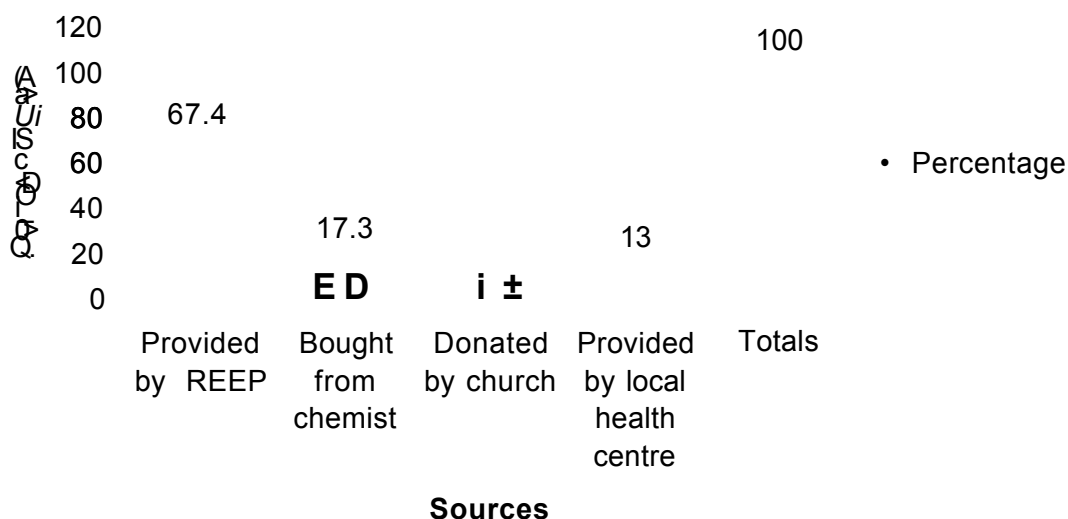
### **The Practice of Accessing Gloves**

Sixty seven percent of the respondents said that gloves were supplied by the CBO (REEP), 13.3% said gloves come from the local health center, 17.3% said that the people were buying from the chemists and 2.3% were getting them as donation from the church (Figure 13).

Data collected through focus group discussions also confirmed that gloves were mainly distributed by REEP. In some occasions, the church donated to the care givers when visiting patients. Some participants noted that well-off families were buying to nurse their patients.

Some participants noted that nursing close family members and relatives with gloves is a new skill that is still being learnt by community members. For this practice to be maintained, availability, affordability and accessibility of the gloves must be guaranteed.

**Figure 13: Sources of gloves: n=307**



### Practice of Referring PLWAs to Health Facilities

Among the respondents, 41.1% didn't know if this referral system is existing (Table 8). However, 33.9% said that it is in place while 24.9% said that the referral system does not exist completely. The major reason given for inadequate referral system was few or no community health workers (62%), and other reasons included patients/relatives being uncooperative (32%), and others (6%), which comprised of those who said that patient can walk (meaning referral is for patients who can't walk) and patients go to hospital on their own volition (meaning that CHWs are not needed). A common complain by patients that

health staff are rude did not appear to be a concern as none of the respondents mentioned it.

The community health workers who were among the participants in the focus group discussions and in depth interviews reported that their judgments regarding patient referral were seldom respected by health personnel at the hospital or health centre. The participants were of the opinion that continuity of patient care on discharge varied from patient to patient since the community health workers were not involved in the processes. In fact some of the majority of the community health workers, said that they were usually surprised to see the patients walking around long after they had been discharged. In places where there are fewer community health workers, continuity of care was limited since the care givers were not informing the CHWs in time because of distance and pressure of work at home.

**Table 8: Existence of referral system for PLWAs: n=366**

<b>Responses on referral existence</b>	<b>Frequency</b>	<b>Percentage</b>
Yes	124	33.9
No	91	24.9
Don't know	151	41.1
Total	366	100

**1**

**Effect of HBC on Referrals of PLWAs**

As far as the rate of referral and stay in hospital for HIV/AIDS patients is concerned, 62.9% felt that it has reduced while 33.3% felt that it has not reduced and 3.8% were not sure as shown in Table 9.

From the focus group discussions and in depth interviews, some participants felt that the rate of admissions and stay in hospital by the AIDS patients had reduced. This view was supported by majority of PLWAs who were among the participants. They went further and confirmed that home based care services have reduced their admissions and stay in hospital drastically.

**Table 9: Reduction of referral due to HBC: n=369**

<b>Response</b>	<b>Frequency</b>	<b>Percentage</b>
Yes	232	62.9
No	123	33.3
Not sure	14	3.8
Totals	369	100

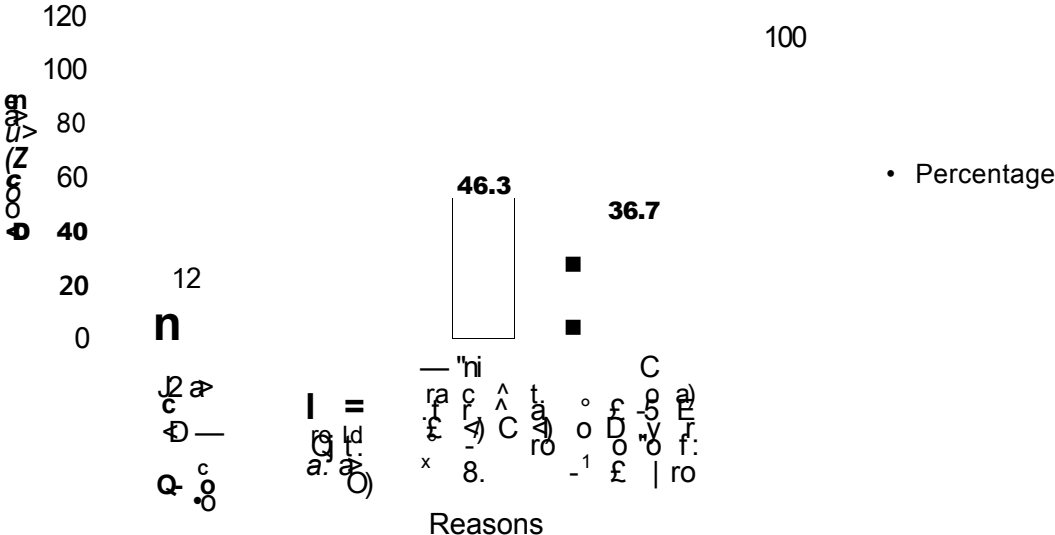
**Reasons for continued of patient referrals to health facilities**

For those who felt that referral and stay in hospital was not reducing (Figure 14 ), gave the following reasons; hospital personnel know better how to take care of patients (46.3%), lack of food and medication at home (36.7%), patients don't like home based care (12%) and relatives getting fed up with constant care (5%).

Participants in focus group discussions complained of general lack of essential medications and other necessary health care supplies that were not available in the home based care kits. The CHWs who were among the participants reiterated that replenishment of home based care kits was erratic leaving care givers with limited supplies to nurse PLWAs.

From in depth interviews, REEP staff noted that with limited resources, the NGO was not able to access enough medical supplies from donors, Government health centres, and sometimes at the district hospital. The participants reiterated that this lack of resources severely compromised effective referral to these health facilities. In cases where medical supplies and drugs were not available at the appropriate referral point, then patients and families were forced to move up the system until they found the supplies they needed.

**Figure 14: Reasons for continued referrals to hospitals: n=121**



## Access to Medication

Sixty-two percent responded that PLWAs get drugs from community health workers of the NGOs (REEP), 15.5% from the District hospital, 10.8% from the local government health unit, 6% from the herbalists and 5.8% from the chemists/clinics as shown in Table 10.

Majority of the participants in the focus group discussions noted the general lack of essential medicines and supplies at the Government dispensary, health centre, and sometimes at the sub district and district hospitals. They went further to say that, the mission hospital at divisional headquarters have drugs, but one has to pay to access them. The participants pointed out that, once a PLWA is registered with REEP, he/she is supplied the drugs from REEP clinic and for those bed ridden, the CHWs deliver the required drugs at home to the care givers.

**Table 10: Access of medication by the HIV/AIDS patients: n=381**

<b>Response</b>	<b>Frequency</b>	<b>Percentage</b>
From local health center (Government or Mission)	41	10.8
Brought by community health worker of REEP	236	62
Going to District hospital	59	15.5
Buying in chemist/clinic	22	5.8
Buying from traditional healers and herbalists	23	6
	381	100



### **Skills and practice scores on home based care**

In order to find out if the care givers have the skills and good practices that depict community support and uptake of home based care each individual respondent, a scoring system was used and categorised into two groups; namely; poor and good. Those who scored 0-3 had poor skills and practice (dependence on the REEP) and those who scored 4-7 had good practice (community support) on home based care as shown in Table 11.

Those with poor skills and practices were 195 (49.6%) while 198 (50.4%) had good skills and practice.

**Table 11: Categorized scores on skills and practice: n=393**

	Frequency	Percent
Poor (0-3)	195	49.6
Good (4-7)	198	50.4
Total	393	100.0

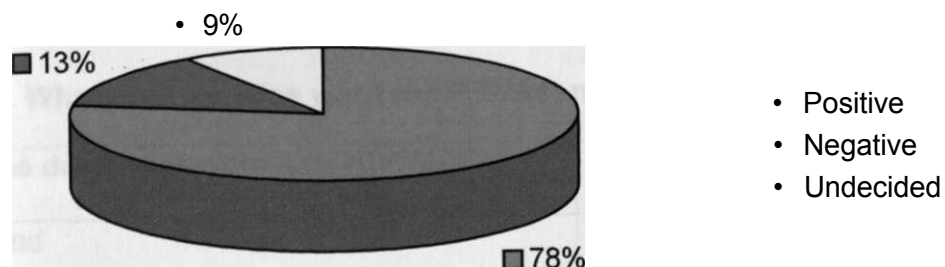
## 5.4 Community attitudes and support towards home based care

### Attitude towards home based care

In Figure 15, the attitudes to home based care were positive for 78% with 13% being negative and 9% being undecided. The reasons for negative attitudes were given as: patients being taken care of better in hospital (34.6%), high expenses (21.2%), heavy burden on relatives (13.5%), limited material support at home (13.5%), inexperienced/untrained CHWs (11.5%), no need of staying at home when sick (3.8%) and too much time taken in nursing patients (1.9%)

Majority of the participants, some of whom included people living with HIV/AIDS (PLWAs), in the focus group discussions were positive about the home based care programme provided by REEP. Some of the PLWAs went further to confess that if it were not for this programme they would have died.

**Figure 15: Opinion on HBC by respondents: n=389**



### **Communities' opinion on what should be done to people with AIDS**

As concerns what should happen to people with HIV/AIDS in the community, 98.6% of the respondents were of the opinion that they should be given sympathy, material support, care and love at home, which is in keeping with the objectives of home based care. On the other hand, one person thought that, they should be condemned, while another one wanted them isolated and kept in hospital and 0.8% of the respondents have no idea as to what should be done to the HIV/AIDS patients (Table 12).

Participants from focus group discussions and in depth interviews noted that, although stigmatization is reducing, discrimination of the PLWAs is still continuing within the communities and at family level. Some PLWAs are still viewed as having loose morals and are a shame to the family. However, the majority of the participants were of the view that PLWAs should be treated with sympathy and given support at home. From the structured interviews, the respondent's opinion was sought through various choices and their responses presented Table 12.

**Table 12: What communities want for PLWAs: n=382**

<b>What to be done to people with HIV/AIDS</b>	<b>Frequency</b>	<b>Percentage</b>
Condemned	1	0.3
Given sympathy, support, care and love at home	377	98.6
Isolated and kept in hospital	1	0.3
Others (no idea)	3	0.8
Total	382	100

### **Family involvement in enrollment of PLWAs in home based care**

The majority of the respondents (81%) said PLWAs were making decisions related to home based care. Some were of the opinion that relatives/family (8.8%), health center staff (6.7%), staff of home based care providers (2.2%) and religious leaders (1.3%) should make decisions for the patient. Majority of the participants from focus group discussions pointed out that, heads of households (especially male) as opposed to PLWAs were making the decisions when to go for home based care.

### **Owning up to the existence of PLWAs in the community**

The respondents knew about the existence (78.9%) of PLWAs in the community as opposed to 2.9% who thought that they were not there and 18.2% who were not sure as shown in Table 13. About 57% of the respondents knew that the PLWAs are registering with the home based care providers, as opposed to those who didn't know (27.4%) about the registration and those who were not sure (15.6%).

Participants from focus group discussions and in depth interviews reiterated that HIV/Aids is still a stigmatized disease in most communities in the division. The PLWAs present in the focus group discussions noted that one way of tackling the disease is by family/community members owning up when one or a member is infected.

**Table 13: Acknowledging of HIV/AIDS patients in the community, n=380**

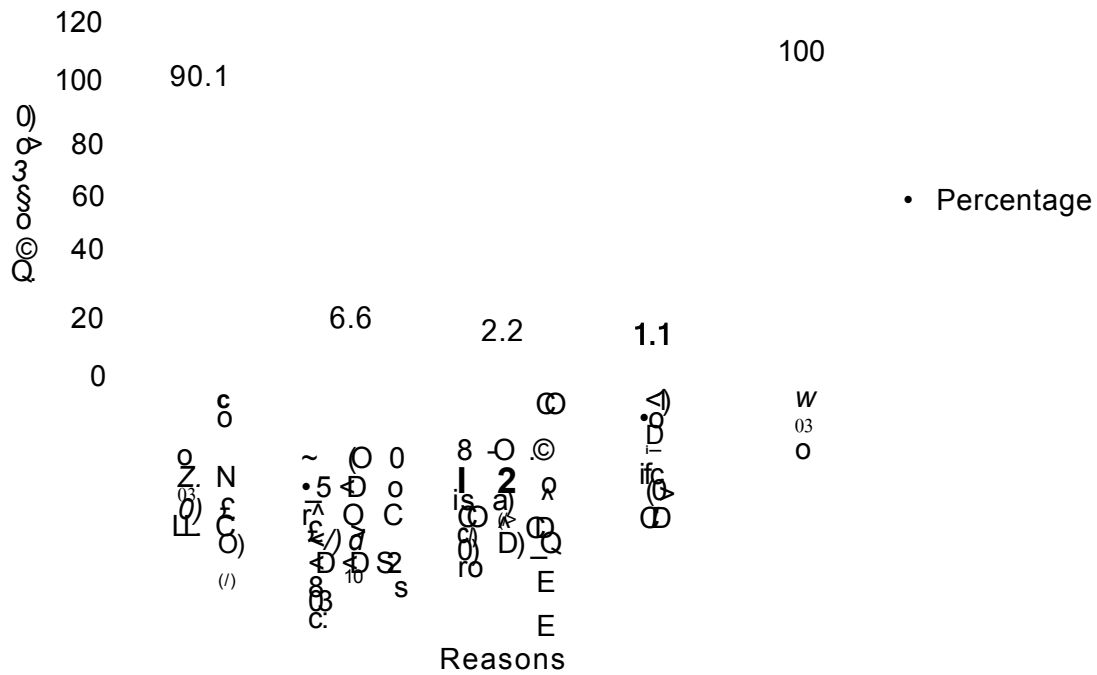
<b>Response</b>	<b>Frequency</b>	<b>Percentage</b>
Yes	300	78.9
No	11	2.9
Not sure	69	18.2
Totals	380	100

### **Reasons for PLWAs not Accessing Services**

For those who thought that PLWAs are not registered with HBC providers, the respondents attributed this to somatization (90.1%), inaccessibility of services due to distance (6.6%), no assistance to registered members (2.2%) and rude staff (1.1%) as represented in Figure 16.

Participants in the focus group discussion lamented that, despite the increase in knowledge and positive attitude towards home based care in Butula Division, stigma surrounding HIV/AIDS is still significant. During the discussions it was emphasized that family caregivers, health care workers and organizations providing care to people at home are stretched to breaking point. Poverty, lack of knowledge, adequate infrastructure of care and food, abuse from PLWAs and limited integrated health care system were identified as root causes of stigmatization.

**Figure 16: Reasons for PLWAs not accessing services: n=91**



**Additional Information that Community Would Like to Have**

On additional information to the community about home based care, the participants from focus group discussions suggested the following:

- More information on home based care focusing on men and the youth
- Patients and care givers should be educated more on medicines and their side effects including antiretrovirals.
- More information on nutrition focusing on locally available foods.
- Information on safe sex when one is positive.
- Provision of Voluntary Testing and counseling (VCT) for children.

This information was confirmed further from structured interviews with 46.5% of respondents requiring more information on nursing care, counseling skills and

type of foods to give and skills of preparation while 21.7% of the respondents wanted additional information on how to support PLWAs at home especially with drug complications, provision of VCT to children of the infected patients and how to have safe sex when one is infected. Out of the total respondents, 31.8% were satisfied that information so far given is adequate.

### **Additional Activities that Community Required to be Implemented**

On what activities the family, community, the providers should engage in to make the programme patient and caregiver friendly, the participants from focal group discussions and in depth interviews had the following suggestions:

- Although World Food Programme is providing food (maize and beans) to the affected households, participants said this is not enough and it does not constitute a balanced diet. They were of the view that, the ratio should be increased and should include oils and salt.
- Affected families should be given funds and skills to engage in income generating activities and raise money to buy more food and medication and also take children to school.
- Although, some community health workers have been trained, the participants felt that they need more refreshers training to catch up with changing environments.
- Usually when the community health workers visit homes, they confine their talk to the patient and the care giver. However, there was a

suggestion that other members of the family should be informed and consulted.

- The programme should be expanded to cover other locations not having community health workers.
- The programme should provide housing and material support especially to widows and orphans.
- The patients are usually worried about education of their children, and an effort should be made to assist the parents pay school fees.
- The community health workers should be supported and their efforts appreciated by the health care system instead of being undermined.

The additional interventions/activities by respondents from structured interviews are similar as those presented in focus group discussions and are outlined below:

- Communities' interventions in terms of knowledge and skills to produce more food (20.8%)
- Income generating activities initiated by communities to improve incomes at household level (16.0%)
- Interventions that strengthen communities to support orphans (9%)
- Increasing the number and training of Community Health Workers (9%)
- Combination food, income generating activities, orphan support programme and increasing CHWs (45.2%)



## **5.5 Relationship between demographic characteristics and knowledge, attitudes and practices**

### **5.5.1 Knowledge**

Table 14 presents the results of the relationships between socio-demographic characteristics and knowledge on home based care.

#### **Sex**

The contingency table shows a high proportion of females with low level of knowledge (64.9%), average (79.5%) and adequate (61.8%) as opposed to the males for low (35.1%), average (20.5%) and adequate (38.2%) levels of knowledge respectively.

There is a statistically significant relationship between sex and knowledge on home based care ( $X^2 = 12.013$  and  $p < 0.005$ )

#### **Age**

As shown in Table 14, the 10 - 19 years age group, the proportions were 14% (low), 3.1% (average) and 6.1% (adequate). For 20-29 year age group, the proportions comprised of 19.3 % ( low), 17.6 % (average) and 22.5% (adequate). In 30-39 year age group, the proportions were 15.8% (low), 30.5% (average) and 32.8% (adequate). For 40-49 year age group, the proportions comprised of 22.8% (low), 24.4% (average) and 25.5% (adequate). For 50 and over age group, the proportions were as follows: 28.1% (low), 24.4% (average) and 16.2% (adequate). The association between age of the respondents and their levels of knowledge was found to be statistically significant ( $X^2 = 22.444$  and  $p < .005$ ).

### ***Level of Education***

For those respondents with no formal education, the levels of knowledge proportions on home based care as shown in Table 14 were 37.5% (low), 34.8% (average) and 19.1%(adequate). Respondents with primary level education had the following proportions: 51.8 % (low), 51.5% (average) and 48.5% (adequate). The proportions for respondents with secondary level of education comprised of 10.7% (low), 11.4% (average) and 28.4% undecided. Those respondents with tertiary education, none had low knowledge, 2.3% had average while 3.9% had adequate knowledge.

The association between the level of education of the respondents and their level of knowledge was found to be statistically significant ( $X^2= 27.244$ ,  $p <0. 005$ ).

**Table 14: Relationship between socio demographic characteristics and knowledge**

<b>Characteristic</b>	<b>Low (1-4)</b>	<b>Average (5-8)</b>	<b>Adequate (9-13)</b>	<b>X<sup>2</sup></b>	<b>P value</b>
<b>Sex</b>	<b>No ( %)</b>	<b>No (%)</b>	<b>No (%)</b>	12.013	P<0.005
<b>Male</b>	20(35.1)	27 (20.5)	78 (38.2)		
<b>Female</b>	37 (64.9)	105 (79.5)	126(61.8)		
<b>Total</b>	57(100)	132(100)	204(100)		
<b>Age (Years)</b>				22.944	P<0.005
<b>10-19</b>	8(14)	4(3.1)	6 (2.9)		
<b>20-29</b>	11(19.3)	23(17.6)	46(22.5)		
<b>30-39</b>	9(15.8)	40(30.5)	67(32.8)		
<b>40-49</b>	13(22.8)	32(24.4)	52(25.5)		
<b>50 and above</b>	16(28.1)	32 (24.4)	33(16.2)		
<b>Total</b>	57(100)	131(100)	204(100)		
<b>Education level</b>				27.244	P<0.005
<b>No formal educa.</b>	21(37.5)	46 (34.8)	39(19.1)		
<b>Primary</b>	29(51.8)	68 (51.5)	99 (48.5)		
<b>Secondary</b>	6(10.7)	15(11.4)	58(28.4)		
<b>Tertiary</b>	0(0)	3 (2.3)	8(3.9)		
<b>Total</b>	56(100)	132 (100)	204(100)		

### 5.5.2 Attitude

Table15 presents the results of the relationships between socio-demographic characteristics and attitude towards home based care.

## **Sex**

The contingency table shows a high proportion of females with positive attitude (68.2%) and negative attitude(67.8%) as opposed to the male gender, who had 31.8% for positive attitude and 32.2% for negative attitude.

There was no statistically significant association between sex and attitude towards home based care ( $X^2 = 0.005$ ,  $p > 0.05$ ).

## **Age**

As shown in Table 15, the 10 - 19 years age group, the proportions were 2.7% (positive) and 10.3% (negative). For 20-29 year age group, the proportions comprised of 20.3 % (positive) and 21.8% (negative). In 30-39 year age group, the proportions were 31.9% (positive) and 20.7% (negative). For age group 40-49 year age group, the proportions comprised of 26.2% (positive) and 20.7% (negative). For 50 and over age group, the proportions were as follows: 8.9% (positive) and 26.4% (negative).

There was a statistically significant association between age and attitude towards home based care ( $X^2 = 14.742$ ,  $p < 0.001$ ).

## **Level of Education**

For those respondents with no formal education, the attitude on home based care as shown in Table 15 were 25.8% (positive) and 31.4% (negative). Respondents with primary level education had the following proportions: 50.0% (positive) and 48.8% (negative). The proportions for respondents with secondary level of education comprised of 21.9% (positive) and 15.1% (negative). Those

respondents with tertiary education, 2.3% had positive attitude and 4.7% had negative attitude.

The level of education was not statistically significantly related to attitude of respondents towards home based care ( $X^2= 3.563$ ,  $p > 0.05$ ).

### ***Attitude on Home Based Care Among Widows***

Among the respondents who were widowed for less than one year, 19.3% had positive attitude while 28.0% had negative attitude. For those who had been widowed between 1-4 years, 44.4% had positive attitude while 32.0% had negative attitude. Those respondents who had been widowed between 5-9 years, 21.5% had positive attitude while 16% had negative attitude. For those who had been widowed for more than 10 years, and 14.8% had positive attitude while 24% had negative attitude.

There was no statistically significant association between duration of widowhood and attitude towards home based care ( $X^2= 2.952$ ,  $p > 0.05$ )

**Table 15: Relationship between socio demographic characteristics and attitude**

<b>Characteristic</b>	<b>Positive</b>	<b>Negative</b>		<b>P value</b>
<b>Sex</b>	<b>No ( %)</b>	<b>No (%)</b>	0.005	P>0.05
<b>Male</b>	96(31.8)	28 (32.2)		
<b>Female</b>	206 (68.2)	59 (67.8)		
<b>Total</b>	302(100)	87(100)		
<b>Age (Years)</b>			14.742	P0.001
<b>10-19</b>	8 (2.7)	9(10.3)		
<b>20-29</b>	61(20.3)	19(21.8)		
<b>30-39</b>	96(31.9)	18(20.7)		
<b>40-49</b>	79(26.2)	18(20.7)		
<b>50 and above</b>	57 (8.9)	23(26.4)		
<b>Total</b>	301(100)	87(100)		
<b>Education level</b>			3.563	p>0.05
<b>No formal education.</b>	78(35.8)	27 (31.4)		
<b>Primary</b>	151(50)	42 (48.8)		
<b>Secondary</b>	66(21.9)	13(15.1)		
<b>Tertiary</b>	7 (2.3)	4 (4.7)		
<b>Total</b>	302(100)	86(100)		
<b>Time of widowhood</b>			2.952	p>0.05
<b>&lt;1 year</b>	26(19.3)	7 (28.0)		
<b>1-4 years</b>	60 (44.4)	8 (32.0)		
<b>5-9 years</b>	29 (21.5)	4(16.0)		
<b>10 year and over</b>	20(14.8)	6 (24.0)		
<b>Total</b>	135(100)	25 (100)		

### **5.5.3 Practice**

Table 16 presents the results of the relationships between socio-demographic characteristics and practice on home based care.

#### **Sex**

The results show a high proportion of females with poor practice (71.3%) and good practice (65.2%) as opposed to the male gender, who had 28.7% for poor practice and 34.8% for good practice.

There was no statistically significant association between sex and practice of home based care ( $X^2 = 1.702$ ,  $p > .01$ ).

#### **Age**

As shown in Table 16, the 10 - 19 years age group, the proportions were 5.6% (poor) and 3.6% (good). For 20-29 year age group, the proportions comprised of 19.0% (poor) and 21.8% (good). In 30-39 year age group, the proportions were 24.1% (poor) and 35.0% (good). For age group 40-49 year age group, the proportions comprised of 26.2% (poor) and 23.4% (good). For 50 and over age group, the proportions were as follows: 25.1% (poor) and 16.2% (good).

There was no statistically significant association between age and practice of home based care ( $X^2 = 9.327$ ,  $p > 0.1$ ).

#### **Level of Education Versus Practice on Home Based Care**

For those respondents with no formal education, the practice of home based care as shown in Table 16 was 32.8% (poor) and 21.3% (good). Respondents

with primary level education had the following proportions: 48.2% (poor) and 51.8% (good). The proportions for respondents with secondary level of education comprised of 17.4% (poor) and 22.8% (good). Those respondents with tertiary education, 1.5% had poor practice and 4.1% had good practice.

There was a statistically significant association between level of education and practice on home based care ( $X^2 = 8.687$ ,  $p < 0.05$ ).

### ***Marital Status***

For those respondents who were not married, 8.2% had poor practice while 9.6% had good practice. As concerns the divorced/separated respondents, 4.6% had poor practice while 3.0% had good practice. In the widowed group, 40.2% had poor practice while 42.9% had good practice. For the married, 45.9% had poor practice as opposed to 43.9% who had good practice. For the orphans, 1% had poor practice while 0.5% had good practice.

There was no statistically significant association between marital status and practice of home based care ( $X^2 = 1.473$ ,  $p \text{ value} > 0.05$ ).

### **Practices of Home Based Care Among Widows**

Among the respondents who were widowed for less than one year, 24.1% had poor practice while 18.1% had good practice. For those who had been widowed between 1-4 years, 40.5% had poor practice while 43.4% had good practice. Those respondents who had been widowed between 5-9 years, 17.7% had poor practice while 22.9% had good practice. For those who had been widowed for



more than 10 years, and 17.7% had poor practice while 15.7% had good practice. There was no statistically significant association between duration of widowhood and practice of home based care ( $X^2= 1.403$  and  $p >0.05$ ).

**Table 16: Relationship between socio demographic characteristics and practice**

Characteristic	Poor (0-3)	Good (4-7)	X*	P value
<b>Sex</b>	<b>No ( %)</b>	<b>No (%)</b>	1.702	p>0.1
<b>Male</b>	56(28.7)	69(34.8)		
<b>Female</b>	139 (71.3)	129 (65.2)		
<b>Total</b>	195(100)	198(100)		
<b>Age (Years)</b>			9.327	p>0.1
<b>10-19</b>	11(5.6)	7(3.6)		
<b>20-29</b>	37(19.0)	43(21.8)		
<b>30-39</b>	47(24.1)	69(35.0)		
<b>40-49</b>	51(26.2)	46(23.4)		
<b>50 and above</b>	49(25.1)	32(16.2)		
<b>Total</b>	195(100)	197(100)		
<b>Education level</b>			8.687	P<0.05
<b>No formal education.</b>	64(32.8)	42 (21.3)		
<b>Primary</b>	94(48.2)	102 (51.8)		
<b>Secondary</b>	34(17.4)	45(22.8)		
<b>Tertiary</b>	3(1.5)	8(4.1)		
<b>Total</b>	195(100)	197(100)		
<b>Social status</b>			1.473	p>0.05
<b>Not married</b>	16(8.2)	19(9.6)		
<b>Divorced</b>	9 (4.6)	6(3.0)		
<b>Widowed</b>	78(40.2)	85(42.9)		
<b>Married</b>	89(45.9)	87(43.9)		
<b>Orphaned (&lt;18 years)</b>	2(1.0)	1(0.5)		
<b>Total</b>	194 (100)	198 (100)		
<b>Time of widowhood</b>			1.403	p>.05
<b>&lt;1 year</b>	19(24.1)	15(18.1)		
<b>1-4 years</b>	32 (40.5)	36 (43.4)		
<b>5-9 years</b>	14(17.7)	19(22.9)		
<b>10 year and over</b>	14(17.7)	13(15.7)		
<b>Total</b>	79(100)	83 (100)		

## 5.6 Results of Logistic Regression Analysis

In order to eliminate the confounding effect among the independent variables (age, sex and education) on the dependent variable (knowledge on home based care) logistic regression analysis was performed. The results showed that age and sex had no significant relationship with knowledge on home based care. Level of education was found to have significant relationship (Wald's statistic( $X^2$ ) =24.43, p value =.000) with knowledge on home based care as presented in Table 17.

Among the education levels, the level of no formal education ( $X^2$  =4.550, p value = 0.033) has significant relationship with knowledge on home based care. From the tabulations, those with no formal education are five times (OR=4.513) likely to have inadequate knowledge on home based care as compared to those with tertiary education (reference group). For those with primary level of education, the likelihood of having inadequate knowledge on home based care is three fold (OR = 2.613) compared with those having tertiary education. Those with secondary education have almost the same knowledge (OR= 0.966) as those with tertiary education.

**Table 17: Logistic regression results between the level of education and knowledge on home based care.**

<b>Level of education</b>	<b>Slope (B)</b>	<b>S.E.</b>	<b>Wald's statistic</b>	<b>Exp(B) (OR)</b>	<b>P value</b>	<b>95.0% C.I. for Exp(B)</b>
<b>Overall</b>			24.434		0.000	
<b>None</b>	1.507	0.706	4.550	4.513	0.033	1.130- 18.022
<b>Primary</b>	.960	0.692	1.927	2.613	0.165	0.673-10.141
<b>Secondary</b>	-.035	0.723	0.002	0.966	0.961	0.234 - 3.985

Reference/ comparison education level was tertiary.

## Chapter 6 DISCUSSION

### 6.1 Socio Demographic Characteristics

#### Sex

Gender inequality facilitates the spread of HIV and exacerbates its impact. Gender and HIV/AIDS are manifested in traditional social safety net mechanisms for women, such as widow inheritance, and the implications of the adverse effects of such practices for women. Research findings in Uganda (*Talor.L et al 1996*) found out that (female gender) women were the main providers of informal care within the home. Many women, particularly in female-headed households, did not own or have direct access to the necessary finances to meet the family's health care needs as expected of them. The women also identified themselves as responsible for a variety of home and agricultural tasks; such activities were frequently disrupted by illness episodes. In a study in Botswana, *Letamo G, 2003* found out that women portrayed more tolerant attitudes towards HIV/AIDS patients, since the burden of caring for sick relatives rests on their shoulders.

Most of the respondents in structured interviews were women 68.2% as opposed to men (31.8%). This gives female: male ratio of 2.15 as opposed to the national figure of 1.05 (*Ministry of Planning and national development, 1999*). Although HIV infections is high in women than men (*Ministry of Health, 2001*), the mortality rates in men are higher than women, and this has been a major contributing factor to high number of widows especially in rural area. Busia District where Butula Division is located has the highest percentage (45.1%) of female-headed households in Western province as compared to the national figure of 36.7 % (

*Ministry of Planning and national development, 1999*). Women heading households with seasonal migrant husbands are vulnerable to HIV infection as their spouses may have other sexual partners at their place of work. In fact, as some female-headed households tend to be poorer than other rural households (with less access to productive resources and to social/support services), the effects of home based care on such families may be severe.

From this study, there was statistical association between sex of the respondents and knowledge of home based care ( $X^2 = 12.013$ ,  $p < 0.005$ ), but for attitude and practice there was no association. Although the number of female respondents was higher than males, their views on home based care are similar to males as shown by the proportions.

### **Age**

Research (*Dians SF et al, 2006*) showed that respondents who were younger, had never married, and had less education expressed greater stigma that was associated with poor knowledge about HIV/Aids and negative attitudes towards home based care. In a related study, *Hamra M et al, 2005*, found out that adolescents showed an ambivalent attitude and undefined fears towards HIV/Aids infected persons compared to adults. In a similar study *Latemo G, 2003*, found out that young people had discriminatory attitudes towards people with HIV/AIDS compared to adults.

Susceptibility and vulnerability to HIV/AIDS and the extent of the impact of the epidemic, has been shown to vary (*Daphne T, 1998*) not only by gender but also

by age group (infants, children, young adults, mature adults and the elderly). Given that the majority of Kenya's population is under 15 years of age and that this largely corresponds to the "window of hope" (age that is relatively HIV/AIDS-free), children and adolescents are a particularly important target group. More generally, the felt needs and constraints of different age groups need to be considered separately in home based care, for example:

Children require health, education, socialization, and skills/knowledge that were not passed on to them from their parents. The youth are concerned with skills, market information and ability to earn a living, because they are increasingly becoming less interested in subsistence agriculture and more enticed by activities that yield quick cash incomes such as trade and high value horticultural crops. For this reason, they may not be interested in home based care activities that will keep them in homes. The elderly as main family providers are worried about how to enhance their food and livelihood security which adds more challenges if they are involved in home based care.

From the structured interviews in this study, the highest percentage of respondents were in the 30 - 39 year age group (29.6%) followed by 40 - 49 year age group (24.7%), 50 - 65 year age group (20.7%) and 10 - 19 year age group (4.6%). Out of the total respondents 57 (14.6 %) had low level of knowledge, 131(33.4%) had average while 204 (52%) had adequate knowledge. For attitude towards home based care, 301(77.6) of the respondents were positive while 87 (22.4%) were negative. As concerns practice of home based

care, 195 (49.7%) identified the poor practices while 197 (50.3%) identified the good practices.

There was a statistical association between the age groups with knowledge (p value <0.005) and attitude (p value = 0.001) on home based care. However, from logistical regression, age and sex were found to be confounding factors to levels of education. The findings are in keeping with the fact that HIV/AIDS is afflicting mostly the reproductive age groups, and some of the respondents could have nursed a relative and/or spouse at home under this programme. From the age of 30 years and above, most couples in the rural areas are in their reproductive period and some even begin to get grandchildren. These findings are also in keeping with the fact that old people are involved in care of their grand children especially in cases where sick person is a single parent or has already lost the spouse. In some cases where both parents have died or are too sick, then the grandparents have to take care of the grandchildren (WHO, Kenya, 2002).

### ***Religion***

The predominant religion in Butula Division was found to be Catholic (52.9%) followed by Protestant (26.5%). The rest (21.6%) is a combination of other religious faiths. This is due to the fact that Butula division is home to a catholic mission established in early 1950s. The Catholic Church has deep roots in the community and as such it has established its own community health and spiritual workers who move around the homes nursing the sick, giving materials support, psycho-spiritual counseling, praying and anointing both the sick and the dieing.

The PLWAs and family members will most likely prefer church counseling and anointing from the same church of affiliation. All these activities are components of home based care that are supposed to complement the efforts of the Government, NGOs and other stakeholders. From the structured interviews, focus group discussions and in-depth interviews, the church was cited as playing a crucial role in home based care. In fact the catholic mission runs the VCT center in the division where REEP refers its clients. From the statistical data, the influence of religion to home based care knowledge, attitudes and practice could not be established since chi square statistic was not valid.

### ***Level of Education***

A half (50%) of the respondents had attained primary level education, with 27% having no formal education, 20.2% reaching secondary level and 2.8% with tertiary education. In the category of low knowledge, the lowest proportion was observed in tertiary level of education (0%) and the highest proportion (51.8%) in primary level of education. As for the average category, the lowest proportion was observed in those with secondary education (11.4%) and highest proportion (51.5%) was observed in those with primary education. For positive attitude, respondents with primary education had the highest proportion of 50%, while tertiary had the lowest (2.3%). Negative attitude had similar pattern with, respondents with primary education having highest proportion (48.8%) and tertiary having the lowest (4.7%). The highest proportion of poor practice was observed in those with primary education (48.2%) as opposed to those with



tertiary (1.5%). Goop practice category also had the highest proportion from respondents with primary education (51.8%) as opposed to those with tertiary (4.1%). From the statistical analysis, the level of education has association with knowledge of home based care ( $X^2 = 27.244$ ,  $p$  value  $< 0.005$ ) and practice ( $X^2 = 8.687$ ,  $p$  value  $< 0.05$ ). Other socio demographic parameters that were associated with Knowledge on home based care are age ( $X^2 = 12.013$ ,  $p < 0.005$ ) and sex ( $X^2 = 22.944$ ,  $p < 0.005$ ). From logistic regression it was found out that sex and age were confounding factors to education on knowledge of home based care. The higher the level of education, the more knowledgeable the respondents were on home based care. Those with no formal education were five fold less likely to have adequate knowledge (OR=4.513) on home based care as compared to those with tertiary education. The ratio was reduced to three fold (OR = 2.613) when education levels move from non to primary. Low level of education has been shown to reduce bargaining power in sexual relationships on the part of the women leading to increased HIV infections. The higher the level of education for members of the community, the better for information and education programmes targeting them. This programme being implemented by REEP has many activities to do with community mobilization and sensitization on HIV and home based care and its success lies in CHWs and care givers understanding the facts of the disease and discarding the myths and beliefs. Given the low level of education (literacy levels: males 76%, females 55.3%) in the district (*Busia District development plan, 2002-2008*) information and education activities need to be repeated at regular intervals for better outputs.

### ***Marital Status***

Majority of the respondents were married (46.0%) while 41.6% were widowed. Although the respondents were not asked the reason for widowhood, there is likelihood that, the majority of spouses could have succumbed to AIDS as the cause of death. Statistically, there was no association between social status and knowledge on home based care (Chi square statistic not valid), attitude (Chi square not valid) and practice ( $X^2 = 1.473$ ,  $p > 0.05$ ). Since HIV is a major contributor to widowhood (*Naamara. W. 1987*), a significant number of the respondents may have had experience with home based care while nursing their spouses. Marital and family status also contribute to susceptibility and vulnerability to HIV/AIDS as well as to the extent of the impact of the epidemic. Household coping strategies of monogamous and polygamous unions are likely to differ, according to spouse rank or status. For instance, a first wife may receive or be able to get more support from the extended family than a second or third wife; in addition, she may have older children who might get preferential treatment in terms of food or schooling within the family. Coping strategies are also likely to differ within polygamous unions: for example, some polygamous families live under the same roof while others live in different dwellings; some wives are fully supported by their husbands while others may have to fend for themselves and their children (*Daphne.T. June 1998, FAO/UNDP publication*)

During focus group discussions it was noted that, many women infected by HIV migrated back to their maternal homes during the later stages of their illness. Frequent illnesses which precipitate deteriorating economic conditions, a sense

of despair and worthlessness had weakened many marital bonds that obligate wives to remain in the nuptial home when husbands die. As such, a significant number of women returned to their maternal homes when their husbands die. Other women return to their homes because they are too frustrated by their in-laws to continue living with them. A few terminally ill women who were participants in this study opted to return home with a hope that children would find a male authority (maternal grandfathers and uncles) and social and emotional security amongst maternal kin.

Widows who were among the participants pointed out that, they may have no legal rights to land and property (due to customary inheritance laws or the difficulties of enforcing existing remedial legislation). From statistical analysis, widowhood was not associated with knowledge (Chi square not valid), attitude ( $\chi^2 = 2.952$ ,  $p > 0.05$ ) and practice ( $\chi^2 = 1.403$ ,  $p > 0.05$ ). The majority (42%) of widows/widowers had lost their spouses 1 -A years before the interview and this is the period REEP programme started in Butula division.

### ***Occupation***

The socio economic status of Butula division is low with 61.3% respondents unemployed and 26.5% self-employed. The average proportion of the respondents who were positive about home based care across all the levels was 77.6%. Statistically, there was no association between occupation and knowledge (chi square not valid), attitude (chi square not valid) and practice (chi square not valid). Low socioeconomic status has been associated with increased

incidences of HIV/AIDS and fast progression from HIV to full blown AIDS (WHO publication 2002).

The government of Kenya has adopted a programme of retrenchment to address some of the financial problems facing the country. This is particularly true for government employees, however, retrenchment has also affected the private sector. Busia has an unemployment rate of 69% compared to the national figure of 52 % ( *Busia District Development Plan 2002 - 2008*) and as a result, there are many instances where families were living in absolute poverty and destitution.

According to the 1999 Kenya population and housing census, Busia District where Butula Division is located, has the second lowest percentage (13.5%) of economically active population in wage employment for the ages between 15 and 64 years ( *Ministry of Planning and national development 1999*). Busia District is also ranked as the 6<sup>th</sup> poorest district in the country with 66% of the population living below the poverty line, with food poverty of 61.4% and hardcore poverty of 50.6% ( *Busia District Development Plan 2002 - 2008*). Average household income on monthly basis is Kshs. 5,141/= with wages contributing to 45.3% of the household income ( *Busia District Development Plan 2002 - 2008*). Low levels of education (literacy levels: males 76%, females 55.3%) also reduce the chances of accessing gainful employment, thus leading to poverty ( *UNICEF publication 2003*). Poverty reduces people to a state of hopelessness and it is a big constraint to the care of patients at home ( *Abdi H.A 2004*).

This state of poverty prevailing in the district was echoed by majority of the participants in focus group discussions. They reiterated that, although World food

programme is providing supplementary food to affected families, this is not enough, and they would like to have more income generating activities to improve the food security at the household level since WFP involvement is temporary. They went further to say that poverty is the greatest threat to HIV/AIDS patients.

## **6.2 Knowledge and Skills on Home Based Care of PLWAs**

Knowledge is one of the major factors that promotes adherence to treatment regimens. With the current trends worldwide of home and community-based services for the management of HIV/AIDS patients, knowledge of CHWAs and care givers about care of the patients will determine the success of the programs. Under the Home based care programme, community health workers were first trained by trainers of trainers (TOTs), who later trained caregivers as per the home based care curriculum, in order to increase their knowledge and on the care of PLWAs at home. Most of the trainers of trainers are medical personnel drawn from neighboring health institutions.

The level of correct knowledge among the respondents was assessed by a number of parameters, which were information on HBC, the components of HBC, the benefits of HBC, disease catered for by HBC, awareness about existence of HBC services and discussions among the community. From the findings, the level of adequate knowledge was 52%, having increased from 30% from inception of the REEP programme.

Although the increase in the level of knowledge is significant ( $Z=15.01$ ,  $p<0.05$ ), this has not necessarily translated into the necessary skills for nursing and counseling PLWAs.

During focus group discussions in this study, majority of the participants who comprised of community health workers, family caregivers and community members, expressed a need to know more about the care and prevention of illness at home. This need was most marked in the care of PLWAs, although knowledge about caring for other chronic illness was also problematic.

Although the community health workers and caregivers present confirmed having received basic education from REEP on basic nursing care, nutrition, use of universal precautions, administration of drugs, use of medical supplies and other forms of patient care, they forgot with time, and as a result, patients were receiving substandard care and family members were putting themselves at risk to infection. One participant reported on this problem:

*"I don't know how to care for my mother.. No one has come to show me what to do. They discharged her from hospital with pills, but I don't know how to care for her sores. I use polythene bags but they break. I don't even have any soap or disinfectant. There is no one to show me what to do".*

The community health workers present reiterated the need for continued education. They reported a lack of knowledge about various treatments for opportunistic infections, and about specific nursing care and treatments for other chronic illnesses. These workers voiced dismay at their inability to provide the

kind of service they knew they should. They also acknowledged their inability to train family caregivers in basic health care practices without refresher trainings. These health workers spoke of the need for continued education on health care matters and how best to counsel and support patients and families. In one focus group, a CHW stated:

*"We lack appropriate skills. We need continued training so that we can give training to the caregivers. There is very little education on patient care given in seminars. We need counseling skills to reduce the tension and also to assist the people to live positively. We need to help and increase community awareness on HIV/Aids so that people are able to ask questions and to understand and deal with their situation. We need continued seminars to become enlightened".*

From studies done in Malawi to find out knowledge, skills and practices of care givers regarding home based care (*Zimba et al 2001*) found out that many families were still taking the PLWAs to hospital for management of minor ailments, thus perpetuating the problem of overburdening the hospital. In a similar study in Botswana, *Ndaba-mbata et al 2000*, found out that knowledge deficit was a common factor among caregivers in the home despite efforts initiated to disseminate information on home care. Consequently there was alarming rates of readmissions to hospital and infection especially grandmothers, suggesting infection during care giving, inadequate knowledge and poor quality care at home. Even the medical staff who are the trainers and thought to have

adequate knowledge and skills are not fairing any better. In a study of knowledge, attitudes and practices of health personnel with regard to HIV/Aids in Madagascar, *Hentgen et al, 2002* found out that scientific knowledge about transmissibility of HIV infection was poor, with 73% of the health staff believing a child born of an HIV-positive woman would systematically be infected and interventions to reduce this risk were unknown, sixty one per cent of the health-workers reported never having advised patients to be tested and less than 10% mentioned correct counseling precautions, and seventy nine percent believed that they were at risk of acquiring AIDS even with protection. In a related study in Thailand, *Mashimo A et al*, showed that in areas with sustained training of community health workers, the communities demonstrated greater depth of knowledge and skills on HIV/Aids and home based care as opposed to those areas with untrained community health workers ( $p < 0.01$ ). This is in keeping with the findings from this study which showed that 75% of the respondents had knowledge and skills of providing protective nursing as compared to 18% who were not using gloves due unavailability (61%) and lack of skills (31%). It was further demonstrated in a study in Kenya, that lack of training (knowledge and skills) on what to do and how to do it as far as nursing of PLWAs is concerned, was exacerbating the fears of caring for the sick and the dieing at home, thereby preferring institutionalized care (*Makokha et al 1989*). In a similar study in Kenya, *Olenja, 1999* found out that care givers, despite having been trained, had inadequate knowledge about HIV/Aids and care expectations thereby by leading to ambivalent behavior towards the sick and sometimes leading to outright



rejection. In another study in Kenya on training process in community based health care, *Kaseje et al, 1987*, found significant changes in the trainees' knowledge practices and behaviour on evaluation, when the trainings were geared towards local problems, perceptions, situations and resources. Despite high levels of knowledge by communities after training, *Shoo R, 1991*, in a study entitled "training primary health care workers to foster community participation" in Tanzania found out during evaluation that communities were demonstrating high levels of knowledge when the training is integrated with agriculture. This shows that training should incorporate sectors that communities associate their livelihoods with, because, some information may look abstract to trainees who have not experienced the problem at hand in their households.

From the statistical data in this study, knowledge was associated with socio demographic factors, namely; sex ( $p < 0.005$ ), age ( $p < 0.005$ ) and education ( $p < 0.005$ ). From logistic regression, sex and age were found to be confounding factors, and the more educated people are the more knowledge they are about home based care.

### **6.3 Attitudes, Stigma and Community Support Towards PLWAs**

Community's attitude, especially care givers towards home based care and HIV/AIDS in general have an influence on the community support and outcome of the disease at personal and family level in terms of the copying mechanisms for the people living with AIDS (PLWAs). Diseases that are least understood and without cure usually lead to stigmatization of those suffering from them. Stigma

being a social construction, has dramatically affected the life experiences of the individuals infected with the human immunodeficiency virus (HIV) and their partners, family and friends since 1984 when it was discovered.

From focus group discussions and in depth interviews, majority of the participants, some of whom included people living with HIV/AIDS (PLWAs), were positive about the home based care programme provided by REEP. Some of the PLWAs confessed that if it were not for this programme they would have died.

From structured interviews, majority of the respondents (78%) were positive about home based care, due to the fact that the patients are nursed in familiar environment, surrounded by their relatives and families. On the other hand 22% of the respondents were negative and undecided about this programme and gave the following reasons:

- Patients better taken care of by hospital staff.
- Expenses involved are high, therefore heavy burden on relatives.
- Limited material support to the affected homes.
- Inexperienced/not well trained CHWs.
- Too much time taken in nursing patient.

The attitude towards HIV positive/AIDS patients was positive, with 99.4% pointing out that they should be given sympathy, care and material support at home while 0.3% of the respondents felt that they should be condemned and another 0.3% saying that they should be isolated in hospital. In a study done in Zambia on home and community care, *Chela et al, 1991* found out that stigmatization by the community of the sick individual cared for at home and

his/her carers is rarely a problem for the individuals involved when carers have been trained, showing a positive attitude. The study further found out that patients continued to attend traditional healers while receiving home care, and seem to achieve symptomatic relief using traditional remedies. This was quite different when the disease first struck with high stigmatisation, when most people preferred to have hospital based care, because it was viewed as a strange disease and hospital care was preferred, as the staff knew best what to do with the disease (*Makokha et al 1989,*). In Eastern Kenya, the Lea Toto Kangemi Outreach Program provides support to families caring for HIV+ children, many of whom are orphaned or soon to be orphaned. A major challenge for these families was found to be stigma attached to the families (*D'Agostino A 2005*). This compares well with a similar study in Hong Kong, where Lau, 2005 found that, the general public had formed some negative perceptions of PLWHA, with discriminatory attitudes towards PLWHA covering different aspects of their life. Study findings from Uganda (*Muyinda H et al, 1997*) suggest that although HIV/AIDS-related stigma has had adverse effects on treatment seeking behaviour of PLWAs and coping mechanisms of their families, a more tolerant attitude is starting to emerge in this area. In Botswana, *Latemo G, 2003* found out that more tolerant attitudes towards a family member with HIV/AIDS appeared to be promoted by the fact that family members have been and continue to care for their sick members through a government project called Community Home-based Care aimed at relieving public hospitals of HIV/AIDS patients. Attitudes towards PLWAs are not any better in health institutions as

evidenced by research in Nigeria, by *Reis et al, 2005* who found discriminatory behavior and attitudes toward patients with HIV/AIDS existing among a significant proportion of health-care professionals, with 40% percent believing that health-care professionals with HIV/AIDS should not be allowed to work in any area of health-care that requires patient contact, 20% percent agreeing that PLWAs behaved immorally and deserve the disease, 12% percent believing that treatment of opportunistic infections in PLWAs patients wasted resources, and 8% indicating that putting PLWAs on anti-retrovirals was a waste of precious resources. In a similar study in Kenya, *Gachingo et al, 2001*, found out that 50% of dentists felt that the risk of HIV transmission in the clinic is high (even with protection) and they preferred PLWAs be treated in dedicated clinics or academic teaching hospitals. In a related study in Madagascar, *Hentgen V et al, 2002* found out that there were negative attitudes towards HIV-positive patients with twenty per cent of the health workers mentioning that AIDS patients should be isolated in quarantine.

Family members play a major role in providing care giving assistance to PLWAs and their families. From studies done in Thailand, *Mashimo et al* found a significant deference ( $p < 0.01$ ) in attitude of community members towards PLWAs in intervention areas (trained community health workers) and control areas. However, the positive attitude did not necessarily lead to community/family support to PLWAs due to care giver burden (physical, emotional, psychological and economical). From a study done by *Faison et al, 1999*, on care giver burden, he found out that, there was a positive correlation between increased activities of

care performed by the caregiver and caregiver burden. This included both the provision of direct care such as bathing and indirect care such as running errands, preparing meals, and performing housework. In a similar study, *Allen et al, 1992*, found out that lack of adequate insurance mechanisms was cited as a major barrier to serving PLWAs. This care giver experience is in line with findings by *Hansen et al/1998* when he evaluated home based care programmes in Zimbabwe (two urban and one rural) and found that the estimated cost incurred per household in caring for bed ridden PLWAs is US\$ 68-103 per household per month, while the cost of a home visit was US\$38-42. A large proportion of these costs were not of direct benefit to the patients, as approximately 56-75% of the total cost per home visit was spent getting to the patient. The high cost of home visits leads to less frequent visits, leaving a larger part of both the burden and the cost of care to the families and the patients.

The time burden on carers was estimated to impose the highest cost on the household. Carers were found to be providing an average of 2.5 to 3.5 hours per day. This time was therefore not available for food production, business activities or employment. Income is also lost due to morbidity of the patients and reduced income to care giver. The resultant effect is to sell assets for the illness at the expense of education for the children (*Okumu G.O, MPH Thesis, 1999*). In a related study in Botswana *Maolosi et al*, found out that, although costs to caregivers remain high in relation to their incomes, home-based care is more affordable and cost-effective than hospital-based care for chronically ill TB patients (commonest opportunistic infection in PLWAs). In a similar study in

Kenya *Wang'ombe et al*, found out that cost-effectiveness improved by 61% when tuberculosis patients were taken care at home as opposed to the hospital. However, it was not clear how the costs related to time, home visits and miscellaneous were factored. This change of attitude in this study noticed in the community is due to the presence of REEP which is funded externally by donors. However, given that it is an NGO with a life span in its programmes, sustainability of the positive attitudes by the community after handover is questionable, when funding cycle ends.

Despite these positive gains in changing attitudes, participants in focus group discussions pointed out that, in Luhya communities, women whose husbands die are frequently encouraged to remarry within the extended family regardless of what caused the death of their spouses. When such husbands subsequently die, lack of adequate knowledge about HIV transmission encourages negative rumours associating the death with the widow's witchcraft. They are thus branded "husband killers", mistreated and encouraged to leave their marital homes.

These findings are in line with a study done in Kisumu, *Ayieko, 2000* (UNDP publication 2000) where many women infected by HIV migrated back to their maternal homes during the later stages of their illness, due to stigmatisation and lack of family support. This was because of prolonged and frequent illnesses which precipitate deteriorating economic conditions, a sense of despair and worthlessness had weakened many marital bonds that obligated wives to remain in the nuptial home in the olden days when husbands passed on.

Mungai. A.G. 2002 (MPH Thesis) observed that, knowledge of HIV positive status makes an individual undergo affective expression of sadness, anxiety, anger, fear, shock, depression, emotional and social withdrawal, feelings of shame, isolation, fatigue, as well as sleeping and eating disorders. This is because, HIV/AIDS is almost always accompanied by the belief that the sufferer is promiscuous or immoral, hence they find themselves being criminalized along with their families and socially ostracized. This has been fatal in terms of coping with HIV/AIDS (*World Health Organization 1993*)

By alienating the affected and infected, HIV/AIDS patients feel they have nothing to gain by protecting themselves and others from infection which in turn breeds helplessness, complacency, indifference and vindictiveness, a perfect condition for the spread of HIV/AIDS (*Muhia, 2001*).

In a similar study done in India, *Bharat S 1998*, found out that in-laws often showed little compassion toward widowed, infected daughters-in-law. Individuals without open sores or lesions were better accepted by family members and perceived as less likely to transmit the virus. Concerns about social stigmatization and isolation prevented many family members from turning to their community for support.

Provision of comprehensive home-based care services is one of the stimulus for people going for VCT and owning up to the disease. A visit to the VCT center in the mission hospital revealed long queues of people willing to know their status. Interview with REEP staff confirmed that during inception of the project,

registration of PLWAs was nonexistent due to high stigmatization and lack of proper information about the disease.

During focus group discussions on what should be done to PLWAs, the majority of the participants said that they should be given sympathy, care & material support at home since they have the necessary information and that the disease can get anyone. However there were participants who felt that some patients under the programmes were engaging in risky behaviour and infecting others, after getting better. The participants felt that the laws prohibiting malicious spread of HIV should be enacted fast to apprehend the offenders, otherwise the gains made towards the acceptance of home based care may be negated.

#### **6.4 Food and Socio Economic Support**

More than half (57%) of the respondents confirmed that HIV/AIDS patients are being registered with Home based care provider (REEP) in the Division, as opposed to 27.4% who said registration is not going on and 15.6% who were not sure. During focus group discussions, it was revealed that clients who test positive for HIV are registered with REEP, and this registration entitles the PLWAs to food supplementation from World Food programme (WFP), visits by Community Health workers and access to cotrimoxazole for prophylaxis. Reasons for not registering with home based care programme, came out as: fear of stigmatization (90.1%) and inaccessibility of services due to limited number of CHWs (6.6%). It should be noted here that registration of the PLWAs with REEP may not be voluntary, given that, there are incentives like food and medication



that are used as pull factors. Given that REEP relies on external donor funds, these incentives of medication and food may disappear when the project comes to a close or when donor funds are withdrawn. Although these incentives were encouraging people to go for Voluntary Testing and Counseling (VCT) in the neighboring Butula Mission hospital, it noted in the focus group discussions that some community members were pleading with VCT counselors to give false positive HIV results in order to get food on monthly basis. The reasoning here is that hunger will weaken a person faster than HIV. Participants reiterated that cases had been reported where individuals especially women who had been denied false positives came back later having been infected when fending for food and other livelihoods.

It is commonly assumed that the extended family in Africa provides a safety net for individuals in times of need. From a study in Uganda on extended family support, *Seeley et al 1993*, found out evidence of limited care in 27 of the 30 families. The reasons given for this by the carers, included lack of food and money for medications and the carer's other family responsibilities. For 17 clients who died during the study period, records of seven cases showed that other relatives were asked to help with care but refused on the grounds of poverty or other commitments. However, in all but one of the cases, extended families did provide assistance for the funeral. In a similar study, *Ntozi, 1997*, found out that financial burden of caring for AIDS patients may be one reason why neighbors, friends, and distant relatives provide only very low levels of care. In Botswana, *Ndaba-Mbata RD et al, 2000*, findings indicated that apart from families lacking

knowledge and skills for providing appropriate care, they were also not aware of the resources available and they lacked professional and material support.

The issue of inadequate food at the household level was raised by all the participants in the focus group discussions. Although World Food Programme is providing supplementary food (beans and Maize) to the affected families on monthly basis, this was not considered enough by the participants, given that, the bread winners in the household could be bedridden or unable to work as it happens in some homes. Participants were of the view that, the programme should involve the affected households in gainful economic activities, so as to buy more food.

Good nutrition is the key to good health and recovery. A well balanced diet, that is advocated for the HIV/AIDS patients just like every one else contains body building foods(proteins), protective foods (Greens and fruits) and energy giving foods (starches). It is recommended that HIV/AIDS patients eat 30% more food than the normal people, due to losses gastroenteritis and repeated fevers (NAS COP, 2000). As much as NAS COP is recommending and advocating for this type of diet, evidence on the ground paints a gloomy picture and suggests otherwise. Constituency Aids Control committees ( CACCs) which is supposed to do resource mobilization for use in home based care in collaboration with District home based care team is yet to be reconstituted.

Interview with World Food Programme and REEP representatives in Busia confirmed that the support to the PLWAs is a temporary humanitarian venture that relies on goodwill of donors and will not sustain food availability at the

household level in the long run. Food security is supposed to be spearheaded by Ministry of agriculture at the District level through extension services. Given that HIV/Aids is a cross cutting national issue inflicting on the able workforce, there should be inter sectoral/ministerial collaboration on the mitigation of HIV/Aids.

In the Luhya community, there existed a traditional social security system provided by one's immediate and extended family. This system has obviously been stretched by the HIV/Aids pandemic and a number of families are barely coping with the effects of HIV/Aids at home. However, despite these overwhelming problems, there were also reports of exceptional acts of kindness and support by individuals, families and communities. From focus group discussions there were reports of community health volunteers providing food, money, and other supplies to needy families. This help was often given by people who were themselves, very poor as reported by the participants. Communities were also noted to rally to the aid of families in need in provision of financial assistance. Harambee, or the mobilization of the community to help families in severe distress, especially for payment of hospital bills, education and funeral expenses, were reported in the focus group discussions as common occurrences, although on small scale from community groupings like youth groups, women merry go rounds and men clubs . Instrumental support was also evidenced in people helping with cultivation or tending animals to help sustain the provision of food for the needy family.

## 6.5 Nursing Care, Counseling and Community Support

Family members play a major role in providing care giving assistance and support to PLWAs and their families. Of the nuclear family, parents, siblings, spouses and children are the dominant Aids patients' primary carers in that order. Other relatives in the extended family also contribute much primary care in terms of care to the patient, helping with washing, feeding, or other care activities. The contribution of neighbours and friends to primary caring and of other relatives as secondary carers is usually small.

During focus group discussion, majority agreed that, after the death of parents, the extended family had to make decisions about the continued care of the widows and children. In most instances, the extended family assumed this responsibility. However, with increasing poverty, participants reported that, this has put an incredible financial burden on the extended family and on their ability to physically house this additional burden like orphans. One care giver summed up this concern:

*"The extended family is too stretched. They can't take the extra children. They are usually taken in but there is a lot of suffering and hunger. Some children are left alone but someone will watch over them, but not much in the way of provisions".*

In a study in Uganda about informal care of illnesses in rural settings, *Taylor et al*, 1996, found that although relatives and friends were seen as a valuable resource, because of poor household proximity and financial constraints they were not always in a position to offer or provide nursing, counseling nor material

assistance. In a study done in Uganda, *Mac Neil, 1996*, found out that for Baganda women, culture care meant responsibility, love, and comfort derived from their kinship, religious, cultural values and reinforced by their health beliefs. They were using these values to continue on in the face of adversity and diminishing the void left by the death of a family member from AIDS. The women also identified themselves as responsible for a variety of home and agricultural tasks. From this study, the decision for a PLWA to be nursed at home was usually taken by the PLWA (81%), family members (8%) and 11% by non family members. This shows a strong family support and commitment to the care of PLWA. Sixty percent of the respondents confirmed that nursing care is done by relatives, as an inherent family support, while 32% by community health workers, 6% by church volunteers and 2% by friends. The female gender was found to be doing most of the nursing with mothers taking 37.3%, wives 35.3%, daughters 14.9%, sisters 10.9%, husbands 0.8%, sons 0.4% and brothers 0.4%. In a related study in Uganda, *Taylor et al, 1996*, found out that women are the main providers of informal care within the home. Despite this, many women, particularly in female-headed households, did not own or have direct access to the necessary finances to meet the family's health care needs as expected of them, and this is why fellow women came in to help. In a similar study in New York, USA, *Smith et al* found out that women relied on their children (especially the girl child) for care while men relied on the wives, with barriers to family support being interpersonal costs, lack of access to services, lack of acceptance by family members, lack of intimacy to close relatives, negative interactions and

fear of disclosure by family members. Nursing care and support in the hospitals where PLWAs are referred was not any better as evidenced by research in Nigeria by Adelekan *et al* 1995, who found out 33% of the nurses would hesitate to nurse PLWAs, while half will not participate in delivery. Also, about a quarter of doctors would hesitate to treat a PLWA while one in three would not carry out surgery despite adequate precautions and most physicians and nurses (75% and 93%, respectively) believed PLWAs should be isolated. In a related study in the same country, Reis *et al*, 2005, found out that nine percent of professionals reported refusing to care for an HIV/AIDS patient, and 9% indicated that they had refused an HIV/AIDS patient admission to a hospital. Fifty-nine percent agreed that people with HIV/AIDS should be on a separate ward, and 40% believed a person's HIV status could be determined by his or her appearance.

In India, Bharat, 1998, found out that, the most supportive care was received by men, even when their female partner was also sick. In-laws often showed little compassion toward widowed, infected daughters-in-law. From Bunting SM, 2001, study, the basic social psychological process that emerged from the analysis of the data was sustaining the relationship between the women as care givers and PLWAs. It was found (Faisan KJ *et al* 1999) that sons, as caregivers, reported significantly less burden than did daughters or other relatives, showing that the male gender was less involved in care giving as opposed to female gender. In order to understand the amount of time spend nursing AIDS patients, respondents gave the times as; when time allows (66.6%), once in two days (13.8%), 1-2 times per day (12.8%) and more than two times per day (6.8%).

Although, most of the respondents (75%) had knowledge and skill of using gloves as a protective measure during nursing of PLWAs, only 17.3% households could afford to provide for the their PLWAs as a family support. The majority (67.4%) were supplied by REEP from donor funds. Given the fact that donor funds are seasonal, families will resort to un protective nursing when the project closes or donor funds are withdrawn. The Constituency Aids Control Committees (CACCS) who are mandated to do community mobilisation, resource mobilisation, and initiation of income generating activities, networking, monitoring and evaluation have not been brought on board yet to cushion the communities.

#### **6.6 Treatment and referral support**

During focus group discussions, half of the participants felt that the rate of admissions and stay in hospital by the AIDS patients had reduced. This view was supported by some PLWAs who were among the participants. They went further and confirmed that home based care services have reduced their admissions and stay in hospital drastically. The other participants reiterated that that hospital environment is hostile and they are often labeled and stigmatized by the health personnel as opposed to their family members at home. Some of the PLWAs said that if antiretroviral, cotrimoxazole and anti TB drugs are given routinely by REEP, then the admissions and stay in hospital would reduce further. When probed further, the same participants reported that sometimes, patients failed to go to the dispensary or health centre due to lack of funds and therefore they go without the prescribed treatment and care.

Participants complained of general lack of essential medicines and supplies at the dispensary, health centre, and sometimes at the district hospital. They pointed out that this lack of resources severely compromised effective referral. If these supplies were not available at the appropriate referral point, then patients and families were forced to move up the system until they found the supplies they needed. In addition, medications and other necessary health care supplies were not available to CHWs to replenish the home based care kits for care givers when nursing PLWAs.

Referral of patients between the community and health facility with involvement of community health workers is not well known to most people who were interviewed. The respondents who answered in the affirmative were 33.9%, while 41.2% did not know that referral system existed and 24.9% actually said that these services were not available. For those who said that services were not available had the following reasons: few/no CHWs available in the community (61.8%), patient uncooperative (32.2%) and 6% of PLWAs were going at their own family support. This shows minimal family and community support for PLWAs to get referral services. From focus group discussions, it was noted that 200 CHWs had been trained from the inception of the programme, but some especially men and the young had dropped due to rural urban migration in such of economic opportunities, lack of incentives and marriages. The two-way referral system involving the patient, community health workers and health unit staff is not well developed in Butula Division and by extension, Busia District. The patient is supposed to be referred by the community health worker with a note so



that he/she is attended to quickly at the health facility. On discharge, the health unit personnel should refer the patient back to the CHW to follow up on taking of medication, nursing and nutritional advice with the care givers (WHO,2003). During focus group discussions and key informant interviews, it was further confirmed that some few CHWs are referring patients with a letter to health units, but on returning no discharge note is given, so CHW get to know that patient is back from third parties. This of course negates the whole purpose of continuum of care, since the home visits by the CHWs become erratic. During in-depth interviews with the District Medical Officer confirmed that the health unit staffs are not giving the referral notes to the community health workers apart from the general clinical discharge summary. The reasons for this were not readily available from the DMO, but he promised to follow up the issue.

Due to limited elaborate referral system by the community health workers and care at home, about 40% of the respondents acknowledged that, the referral and stay of patients to hospital was not reducing. The reasons given were that hospital personnel know better how to take care of patients (46.3%), implying that the caregivers did not have adequate knowledge and skills to take care of patients at home. The other reason was lack of food and medication at home (36.7%), implying limited economic support from the PLWAs and families. Twelve percent of the respondents reiterated that patients don't like home based care, implying that stigmatization and lack of family support. Lastly, 5% of the respondents confirmed that relatives were getting fed up with constant care, due to the burdens that comes with the care.

More than half of the respondents (62%) said that they are accessing the drugs through REEP as opposed to 15.5% from District Hospital, 10.8% from the local health center, 6% from herbalists and 5% from chemists. From this study, it is evident that drugs are coming through REEP which relies on donor funds. With completion of the project or withdrawal of donor funds, the provision of drugs will eventually cease. The commonest opportunistic infections in HIV/AIDS patients are Malaria, Tuberculosis and Gastroenteritis. Diagnosis of Tuberculosis can only be done at Busia District Hospital (40 Kilometers from Butula) for the patients to get drugs under the TB and Leprosy control Programme. Given the distance and the series of investigations needed, many people can't afford the transport and may not be diagnosed, till it is too late. In a similar study in Nairobi *Wasonga, 2005* found out that distance and transport costs and cost sharing at the health facilities were hindering access to antiretrovirals, especially to most poor.

During focus group discussions, the Principle Researcher was shown cards by the participants, which enable them to access cotrimoxazole prophylaxis for pneumocystis carinni and even anti retrovirals at REEP pharmacy. The officials of REEP confirmed that the supply of these drugs is erratic since financial capability of the CBO is limited.

The lack of accessibility to ARVs by the majority of HIV/AIDS patients in Butula, just like other patients in Kenya remain a major obstacle to management of HIV since therapy is currently restricted to major hospitals (*Wasonga, 2005*). The standard care in ARV therapy requires viral load monitoring and CD4 cell counts. Both of these are expensive and available in only limited institutions in the

country, a factor that hinders access to bigger portion of the population (Ministry of Health, 2003).

Although Busia District Hospital is providing ARVs at a small cost sharing fee, the patients in Butula cant access this service because of distance and cost sharing.

The participants complained about the side effects of drugs leading to loss of appetite and lack of compliance by the patients and wanted more information on how to manage this. Although the Ministry of health in Kenya just like other developing countries, is advocating for home based care, the availability of the drugs to the PLWAs is limited to the District hospitals which are inaccessible to majority of the PLWAs in rural areas (*Johannes Van Dam, 2001*), and due to widespread poverty, the cost sharing on ARVs is also a hindering factor.

From the Government guidelines, the Aids Control Committees are supposed to collaborate closely with District Health management Teams (DHMTs), District Home Based Care Committees (DHCCs), local and District hospitals, health centres and NGOs/CBOs that are providing home based care with aim of increasing accessibility to medication. This is yet to bear fruit since the home based care kits are not replenished and drugs are not readily available.

## 6.7 Sustainability of Home Based Care Programmes

During focus group discussions and in depth interviews participants noted that, the selection of the community workers was not transparent. It was pointed out that majority of CHWs were selected based on their relationship with local authorities and management of the NGOs sponsoring the programmes.

Participants pointed out that, the ideal CHW should be middle aged women, married within the community and having primary level education.

Interview with REEP confirmed that they relied on the local authorities to select the CHWs, majority of whom were women with primary level education, and all were taken for training as counselors. However, the level of understanding, knowledge and practice after the training depended on age, sex, level of education and attitude of the individual CHWs. During the study, REEP had 200 CHWs serving a population of 125,000 people over an area of 245 Km<sup>2</sup> (*Busia District Development plan 2002-2008*). Given the national total fertility rate of 5 (*KDHS 2003*), the average family size is 7 members, and this gives the CHW: population ration of 1:90 as opposed to ratio of 1:25 (*MOH, 2006*) recommended by Ministry of Health. With the HIV prevalence rate of 14.2% in Busia District (*NASCOP, 2005*), the estimated number of PLWAs in Butula division is 17,750, with a CHW: PLWA ratio of 1:90 as opposed to 1: 10 (*NASCOP, 2003*) recommended by NASCOP. REEP remunerated community health workers Kshs 2000/= per month as transport allowance, because donor funds are not sustainable for salaries, since they are recurrent expenditures. Moreover, these

allowances are paid when money is available and this demotivates CHWAs.

Given this taunting task of care giving, amid limited resources, REEP reported high turnover among community workers, which disrupts the home based care services (50 out 250 CHWs had dropped out during the time of this study).

Majority of the participants in focus group discussions pointed out that, despite the home based care and nursing they perform, the health professionals often resisted the involvement of community members in care and treatment. Because of these attitudes from health professionals, community health workers are viewed simply as local helpers who can temporarily take on tasks the formal health care delivery system lacks the resources to perform. By so doing, CHWs are primarily being looked at as a cheap way to deal with human resource constraints. For sustainability, community health worker programmes should be seen as part of a broader strategy to empower communities, enable them to achieve greater control over their health and improve the health of their members.

PLWAs in the focus group discussions felt that, since they are conversant with HIV/Aids, majority of them should be selected as CHWs and supported to train care givers and at the same time nurse fellow PLWAs. These practices were noted by WHO in Thailand and South Africa , where trained community members worked within formal health centres with PLWAs, and participated as counselors, helping patients to make treatment plans in order to enhance treatment adherence (*WHO,2004*). These practices implied fostering appropriate attitudes

and skills among health professionals to work with communities and put in place incentives at health center level for community health workers. Resource allocation at District level must strengthen the front-line facilities that form the interface with communities. This means putting in place specific participatory arrangements to build community capacity for a greater involvement, ownership and sustainability.

Qualitative data indicated that the programme implemented by REEP has a sustainability risk since more than 60% of drugs, gloves and kits are donor dependent. The same applies to training of community health workers and monthly supplementary foods from World Food programme. The realization that donor dependent programmes are not sustainable, the Ministry of Health strategy for the delivery of Level 1 services is to build community based initiatives into existing programmes, based on available resources. The Ministry notes that home based care programmes can be self sustaining by the community if properly governed by the community with systems of CHW selection, training, remuneration, accountability and transparency established and practiced (MOH, 2006). These findings are in keeping with a study carried out by WHO in Haiti and Rwanda, where community organizations and PLWAs had been delegated and incorporated into tasks traditionally performed by facility-based formal health workers, like antiretroviral treatment. In these programmes, trained community members took the responsibility for the initial selection and counseling of patients for antiretroviral treatment, monitoring side-effects and supervision of drug compliance (WHO, 2004).

## **Chapter 7 CONCLUSION AND RECOMMENDATIONS**

### **7.1 Conclusion**

#### **7.1.1 Knowledge on home based care**

The level of knowledge on home based care was found to be low with 52% of the respondents having adequate knowledge as compared to 30% during the inception of the REEP project. The level of education of respondents was found to be highly associated with knowledge on home based care (  $X^2= 24.43$ , p value =.000). Those with no formal education were almost five times (OR=4.513) more likely to have inadequate knowledge on home based care as compared to those with tertiary education.

The likelihood of having inadequate knowledge for those with primary level of education on home based care is almost three fold (OR = 2.613) compared with those having tertiary education. Those with secondary education have almost the same knowledge (OR= 0.966) as those with tertiary education.

#### **7.1.2 Attitude and community support**

The attitude towards home based care was notably positive (77.6 %), with 98.6% of the respondents reporting that PLWAs should be given sympathy, material support, care and love at home. The positive attitude towards the programme has translated into 80% of the respondents owning up and acknowledging that PLWAs live within the community. Stigmatization is high but reportedly coming down as evidenced by increasing voluntary testing and counseling at Butula VCT center, testimonies of PLWAs at funerals and public barazas and increasing

number of participants in post test support clubs. The willingness to support home based care by individuals, families and communities is there but this has been compromised by prevailing poverty, overstretching of the traditional/cultural cushioning structures and caregiver burden/burnout. This affects mostly the women, who are the primary care givers with limited resources. Community uptake of home based care is not sustainable under these circumstances since most of the resources spent here are from external donor funds.

### **7.1.3 Practices on home based care**

Although the increase in knowledge had impacted useful life skills in care givers, this had translated marginally into good practices (50%) because of the underlying factors of poverty, food insecurity, and inadequate home based care kits at the family level. Referral of PLWAs was still practiced, despite stigmatization in the health facilities.



## **7.2 Recommendations**

### **7.2.1 National level (Legislative and policy)**

- The study recommends establishment of Home based care Fund (HBCF) through an act of parliament, or a specific allocation from Constituency Development Fund (CDF) to fund home based care activities aimed at initiating income generating activities for self help women groups.
- The Ministry of health should work towards the enactment of insurance Bill that will enable the PLWAs to access health services, especially for opportunistic infections and antiretrovirals since the current funding from Global fund for these drugs and Tuberculosis is not sustainable.
- Ministry of Health (NASCO) should redefine guidelines for selection of community health workers. The community health workers should be PLWAs or married middle aged women who are able to read and write with demonstratable attitudes towards care of patients. The community health workers should be linked to local administrative structures and health facilities for supervision and cash compensation for level of effort.

### **7.2.2 District level (programmatic)**

- MOH/DHMT/DHBCC should be the entry point of Home based care programmes to enhance resource mobilization, capacity building, coordination, collaboration, monitoring and evaluation of activities to

ensure equitable distribution of services within the district and avoid duplication.

- Inter-sectoral collaboration of the formal institutions (health, agriculture education, welfare, etc.) should be strengthened by the District Development Committee (DDC) at both District and divisional levels to effectively support and train informal rural institutions (women, community, youth, PLWAs and men groups) to boost food production, income-generation and poverty alleviation activities.

### **7.2.3 Community level**

#### **Knowledge, skills and practices**

- REEP together with local health facility workers should continuously train the community health workers to develop life skills through demonstrations and instructions based on home based care curriculum and immediate learning needs for care givers.
- REEP should use peer educators and PLWAs to engage in activities that explicitly promote home based care for PLWAs. Professional talks from retired clinicians, nutritionists, psychiatrists, social scientists and economists should be incorporated in the activities to further reinforce the knowledge and skills gained by CHWs and care givers.

### **Attitude and community support**

- REEP should employ a strong Behavior and Communication (BCC) component designed by PLWAs to create demand for services. REEP should also explore ways that are culturally sensitive to facilitate discussion on how to overcome social conservatism with regard to HIV/Aids, stigmatization and home based care.
- Increased Community participation through participatory approaches to generate appropriate community based information system for dialogue and health promotion. This will increase acceptance, understanding and involvement of PLWAs thereby reducing stigma.
- Local authorities (Divisional Officer and chiefs) to mobilize traditional leadership structures to reconstruct and strength the extended family and kinship systems so that they are able to continue to perform their vital function of providing support for PLWAs.

#### **7.2.4 Sustainability**

Home based care activities should be build into existing plans by Ministry of Health and Constituency Aids Control Committees (CAACs) and based on available resources, instead of depending on donor funds. With the help of CACCs community groups can access more funds from Constituency Development Fund (CDF) for home based care activities. In so doing

communities and PLWAs will play a leading role in joint planning, decision making, and management of funds.

#### **7.2.5 Further research**

- Further research to find out factors that influence referral of HIV/AIDS patients to hospital in areas where CHBC is implemented.

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## **APPENDIX I**

### **Home based care questionnaire for structured interviews**

**Assessment of Knowledge, attitudes and practices (KAP) on home based care of HIV/Aids patients in Butula Division, Busia district.**

**Participants are guaranteed in advance that information received during the interview will be treated in total confidence, and are requested to participate with sincerity.**

**Serial no:**

Location:

Date:

#### ***Introduction***

**Hello,**

**My name is.....and I am interested in knowing more about home-based care knowledge, perceptions and practice among your community. The information you give is very important and therefore be sincere in your responses. I assure you that information received will be treated in total confidence**

**Thank you and welcome.**

PART 1

SOCIO DEMOGRAPHIC DATA

- 1.1 Name of the village
- 1.2 Sex of respondent
  - (a) Male
  - (b) Female
- 1.3: Age of respondent in years.
  - (a) 10-19
  - (b) 20-29
  - (c) 30-39
  - (d) 40-49
  - (e) >50
- 1.4: What is you religion?
  - a) Catholic

- b) Protestant
- c) Muslim
- d) Traditional
- e) None
- f) Others specify

1.5: Levels of Education.

- a) None
- b) Primary
- c) Secondary
- d) Tertiary (Colleges and university)

1.6: Social status

- (a) Not Married
- (b) Divorced/Separated
- (c) Widowed
- (d) Married
- (e) Orphan (Applies to respondents below 18 years)

1.7: If widowed in **No 1.6**, over what duration?

- (a) <1 year
- (b) 1-4 years
- (c) 5-9 years
- (d) >10 years

1.8: What is your occupation?

- a) Unemployed
- b) Student/pupil
- c) Casual work
- d) Self employed (Income generating project)
- e) Community health worker/counsellor/home visitor/care giver
- f) Salaried employment.

## **PART 11**

### **KNOWLEDGE OF HOME BASED CARE**

1.9: Have you ever heard of the phrase "home based care"?

- (a) Yes
- (b) No

2.0) If yes in 1.9 from which sources did you hear about it? (Tick against sources mentioned spontaneously)

- (a) Hospital/Health Centre workers
- (b) Newspapers/ Magazine/ Posters etc

- (c) Relatives/Friends
- (d) Spouse/parent/child.
- (e) Community health workers from CBOs like REEP, BUCOS etc
- (f) Community Health Workers from Health centres
- (g) Community health workers from church.
- (h) Others Specify:

2.1: Who provides home based care services in this division?

- (a) Government health workers
- (b) Community based organisations (CBOs)
- (c) International organisations
- (e) Church organisations
- (f) Others. Specify

2.2: Home based care activities are directed to which disease(s)?

- (a) AIDS (Ukimwi)
- (b) Accident injuries
- (c) Common cold
- (d) Malaria
- (e) Others Specify

2.3: If the answer in 2.2 above is AIDS, then are the HIV/AIDS infected people you know in this division aware about these services?

- (a) Yes
- (b) No

2.4 Are the people in your community educated about home based care?

- a) Yes
- b) No

2.5: If yes in 2.4 above, how were/are the people educated about Home based care?

- a) Community Health workers of CBOs/government/church
- b) Leaf lets/ pamphlets/ book lets and other information materials.
- c) Mass campaigns at public functions by CBOs/ government/church
- d) Peer educators from CBOs
- e) Others specify

2.6: From your own knowledge, what do you think constitutes Home Based care?

- (a) Counselling the infected and affected.
- (b) Praying for the sick.
- (c) Good nutrition
- (d) Treatment of opportunistic infections.
- (e) Nursing of the sick.

- (f) All the above.
- (g) Surgery.
- (h) Others Specify

2.7: What do you think are the advantages/benefits of Home Based care?

- (a) Its cheap
- (b) Patients are nursed in familiar environment
- (c) Good support from the family members and relatives
- (d) Patients are handled with dignity
- (e) All the above
- (f) Others Specify

2.8: Have you ever discussed home based care with other people?

- a) NO
- b) Yes

2.9: If yes with whom?

- a) Relatives
- b) Friends.
- c) Health Staff
- d) Staff of CBOs/Health centres/church
- e) Others specify.

### **PART III**

#### **PERCEPTION AND ATTITUDES OF HOME BASED CARE MISCONCEPTIONS**

3.0: What is your opinion of home based care programmes in this division?

- a) Positive
- b) Negative
- c) Un decided

3.1: If negative in 3.0 What are your reasons?

3.2: What should be done to people with AIDS in your community?

- (a) They should be condemned
- (b) They should be given sympathy and love
- (c) Should be given material support and care for at home.
- (d) They should be isolated and kept in hospital.
- (e) Others, specify

3.3: In your own opinion who is supposed to make decisions related to home based Care?

- (a) Patient

- (b) Family/relatives
- (c) Health centre staff
- (d) Staff of home based care providers
- (e) Religious leader
- (f) Others specify

**PART IV:  
PRACTICE OF HOME BASED CARE**

3.3 Are there AIDS patients in your community/village or elsewhere in the division?

- a) Yes
- b) No
- c) I don't now/ not sure

3.4 If yes in 3.3 above are the AIDS patients registering/registered with home based care providers?

- a) Yes
- b) No
- c) I don't know/not sure

3.5: If no in 3.4 above, why do you think so?

- a) Fear of stigmatisation
- b) Home based care providers staff inaccessible (Distance)
- c) No material assistance to registered members from providers
- d) Staff are rude
- e) Others Specify

3.6: Are the AIDS patients being referred to and received from hospital by trained community health workers from the home based care providers?

- (a) Yes
- (b) No
- (c) I don't know

3.7; If no in 3.6, in your opinion what are the reasons?

- (a) No Community health workers in the community
- (b) The community health workers are few
- (c) The relatives/ patient are uncooperative
- (d) The health personnel in the hospitals are uncooperative
- (e) Others specify

3.8: In your opinion, has the rate of referral of AIDS patients and stay in hospital reduced ever since the home based care programme began?

- (a) Yes
- (b) No

- 3.9: If no in 3.8 above, what do you think are the reasons?
- a) Patients don't like home based care
  - b) The relatives get fed up with constant care.
  - c) Relatives think the hospital personnel know better to take care.
  - d) Lack of food and medication at home
  - e) Others, specify
- 4.0: How do AIDS patients access medication in your community?
- (a) Going to local Health centre (Government/mission)
  - (b) Brought by the community health worker (CBOs)
  - (c) Going to District Hospital
  - (d) Buying from the nearby chemist/clinic
  - (e) From the traditional healers/herbalists
  - (f) Others Specify
- 4.1: Who does the nursing care for AIDS patients in your community?
- (a) Friends
  - (b) Relatives
  - (c) Community Health workers from CBOs/government
  - (d) Church volunteers
  - (e) Others. Specify
- 4.2 If relative in 4.1, which one in particular
- (a) Wife
  - (b) Mother
  - (c) Daughter
  - (d) Son
  - (e) Father
  - (f) Husband
  - (g) Brother
  - (h) Sister
  - (i) Others Specify
- 4.3: At what frequency is nursing done for the AIDS patients?
- (a) > 2 times a day
  - (b) 1-2 times per day
  - (c) Once in two days
  - (d) PRN (When time allows)
- 4.4 How is the nursing of AIDS patients done?
- a) Using gloves and protective clothing.
  - b) Bare hands
  - c) Others. Specify

4.5: If by "using gloves and protective clothing" in 4.4, why do you think this should be the procedure?

- a) The carers can also be infected
- b) The carers can re infect the patient with AIDS
- c) The patients once infected have no value and can be handled that way.
- d) Others Specify

4.6 If by " using gloves and protective clothing" in 4.4 above, How are they accessed by the people who need them?

- a) Provided by CBOs providing home based care.
- b) Bought from chemist
- c) Donated by Church
- d) Provided by local health centre
- e) Others Specify

4.7: If by "bare hands" in 4.4, why do you think this is so?

- a) Patient will think the carer is in human.
- b) Relatives/ carers think its in human
- c) Relatives cant afford the gloves/ protective clothing( Home based care kit)
- d) Others Specify

4.8 What additional information would you like to know about Home based care

4.9: What additional interventions/measures/activities would you like home based care providers to put in place so as to make home based care patient friendly.

5.0: Is respondent PLWA

- a) Yes (confirm with VCT card)
- b) No

**Thanks a lot for sparing your valuable time for this interview and may God bless you.**



## **APPENDIX II**

### **Home based care in depth interview guide**

**Assessment of Knowledge, attitudes and practices (KAP) on home based care of HIV/Aids patients in Butula Division, Busia district**

**Participants are guaranteed in advance that information received during the interview guide will be treated in total confidence, and are requested to participate with sincerity**

**SERIAL NO.**

**LOCATION**

**DATE**

**Introduction**

**Hello,**

**My name is.....and I am interested in knowing more about home based care knowledge, perceptions and practice among your community. The information you give is very important and therefore be sincere in your responses. I assure you that information received will be treated in total confidence.**

**Thank you and welcome.**

**PART 1**

**SOCIO DEMOGRAPHIC DATA**

1.1 Name of the village

1.2 Sex of respondent

- a) male
- b) female

1.3 Age of respondent in years (write exact age in years)

1.4 What is your religion?

- a) Catholic
- b) Protestant
- c) Muslim
- d) Traditional
- e) None
- f) Others specify

1.5 Levels of education

- a) None
- b) Primary
- c) Secondary
- d) Tertiary (Colleges and University)

1.6 Social status

- a) Not married
- b) Divorced/Separated
- c) Widowed
- d) Married
- e) Orphan (applies to respondents below 18 years)

1.7 If widowed in No. 1.6, over what duration? (write exact duration)

1.8 What is your occupation?

- a. Unemployed
- b. Student/pupil
- c. Casual worker
- d. Self employed (income generating project)
- e. Community health worker/counselor/home visitor
- f. Salaried employment

## **PART II**

### **Knowledge, attitude and practice of home based care**

1.9 Have you ever heard of Home Based Care? If so name the sources

2.0 Who is providing home based care services?

2.1 Which type of patients are benefiting (supposed to benefit) from home based care services?

2.2 What is your attitude towards home based care programme for HIV/AIDS patients?

2.3 How do you compare the access of medication for HIV/AIDS patients before and after the inception of the programme?

2.4 Are the HIV patients getting adequate nursing care after the inception of the programme? If no what are the reasons?

2.5 Who in the family should provide Home Based Care and why?

2.6 How do you compare the HIV/AIDS patient referrals to and from hospital before and after the inception of the home based care programme?

2.7 What do you think the home based care providers should do or put in place to make this home based care patient friendly?

2.8 Do the AIDS patients prefer to be nursed in hospital or at home? (Reason for either response)

## **APPENDIX III**

### **Assessment of Knowledge, attitudes and practices (KAP) on home based care of HIV/Aids patients in Butula Division, Busia district**

#### **Guidelines for focus group discussions**

##### **A:INTRODUCTION**

The facilitator will greet the participants and initiate introduction of him/herself and all members of the group will say their names. The facilitator will then introduce the subject of discussion to the members and its importance.

##### **B: QUESTION ANSWER SESSION**

The facilitator will put across questions relating to the knowledge, attitudes and practice of home based care to the group for discussion. Any myths and wrong perceptions should be put in the correct perspective on the spot.

**The following questions will serve as a guide.**

##### **i)Knowledge**

- a) Have you heard of home based care?
- b) If so, what was the source of information?
- c) Who provides home based care and for what disease?
- d) What constitutes home based care? (What are the components of home based care?)
- e) Are the people educated on home based care and by whom?

##### **ii) Attitude**

- a) What is your perception of home based care programme?
- b) Is the programme patient and care giver friendly?

##### **iii) Practice**

- a) Is there continuity of patient care from the health facility to home ever since the programme began?
- b) How do you compare the rate of admission and length of stay in the hospital of patients before and after this programme began?
- c) Are the patients and care givers visited on regular basis by the community health workers church groups?
- d) How do affected families access food and medication?
- e) Do patients have access to home based care kits?
- f) Who in the family gives care to the AIDS patients at home?
- g) What additional information would you like to have on home based care?
- h) What activities should the family, community, the providers engage in to make the programme patient and care giver friendly?