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HOME BASED CARE FOR HIV/AIDS IN THE AGOGO SUB DISTRICT

BY

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DECLARATION

I declare that this dissertation has been the result of my own field research. Where other people's works have been cited, this has been duly acknowledged in the references. This dissertation has not been submitted towards the award of any degree nor is it being submitted concurrently in candidature for any other degree.

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DEDICATION

This work is dedicated to my husband Mac, my children, Kobby, Megan and Allan, and to my mother and father for their support and encouragement during the period of this course.

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LIST OF ABBREVIATIONS:

AIDS	Acquired Immure Deficiency Syndrome
CHAG	Christian Health Association of Ghana
CHBC	Community Home-Based Care
FWOPWLA	Family Members without AIDS
GPA	Global Programme on AIDS
HBC	Home-Based Care
HIV	Human immunodeficiency Virus
IE&C	Information, Education, and Communication
MOH	Ministry Of Health
NACP	National Aids Control Programme
NGO	Non- Governmental Organization
PHC	Primary Health Care
PLWHA	People Living With HIV/AIDS
TASO	The AIDS Support Organization
TBA	Traditional Birth Attendant
UNAIDS	Joint United Nations Programme On HIV/AIDS
W.H.O.	World Health Organization

Abstract

AIDS is now a major cause of morbidity and mortality in most Sub-Saharan African countries, in the absence of a cure, many adults suffer long chronic illness, medical services already inadequate are over stretched. Many hospitals are unable to deal with the huge caseload of patients with HIV/AIDS, this has necessitated strategies for AIDS management that combines Home-based care (HBC) with hospital intervention where required. The form that a HBC programme takes depends on the socio-cultural system prevailing in the area.

This study examined the knowledge, attitudes, behaviour and practices of home-based care community volunteers, in- family caregivers of people living with HIV/AIDS, and family members without AIDS in eight communities with a home-based care programme in the Agogo sub district of the Ashanti Region of Ghana. The study further examined community participation in the home-based care programme and the effect of the programme on the lives of people living with HIV/AIDS.

Both qualitative and quantitative methods were used to elicit information from participants. Thirty-two participants formed the Focus Group Discussion, while sixty-five people were involved in the survey. In-depth interviews were held with the coordinators of the home-base care programme and people living with HIV/AIDS.

The study found an increase in knowledge and positive attitude towards people living with HIV/AIDS amongst HBC community volunteers and in-family caregivers; this had translated into a change in sexual behaviour. Family members without AIDS had average knowledge and negative attitude towards people living with HIV/AIDS, fewer of them had changed sexual behaviour.
Although the communities' sense of ownership of the HBC programme was rather low, PLWHA who have accessed the HBC programme have free medical care and feel less stigmatised.

The study recommends that government integrate home-based care into existing activities for HIV/AIDS in other to overcome social barriers to care, and to serve as a source of information, education, and communication on HIV/AIDS.

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND

Only two decades ago, Human Immunodeficiency Virus (HIV), and Acquired Immune Deficiency Syndrome (AIDS) were almost unknown; today no nation on earth can escape its consequences.

The virus can live in a person's body for several years without causing ill effects. Transmission from one person to the other is through sexual activity or blood. It can also be passed from mother to child during childbirth or pregnancy. As the virus takes effect, the person suffers from repeated infections like respiratory and skin infection, diarrhoea, gastro-intestinal tract infection, central nervous system disorders and inflammation of the genitals. The virus finally breaks down the body's immune system, which leads to death (Mwale 1992).

Public reaction to AIDS has been varied from denial, stigmatization, and indifference to violence. The consequences of AIDS on families, health service, and socio-economic stability are enormous and every effort must be made to curtail the spread of this disease. The impact of the AIDS pandemic is being increasingly felt in many countries across the world. In countries already burdened by huge socio-economic challenges, AIDS threatens human welfare, developmental progress, and socio-economic stability on an unprecedented scale (UNAIDS, 2001).

In the past decade, the global strategy against AIDS was focused primarily on prevention, regardless of the effectiveness of preventive efforts being made today and advances in treatments, the number of persons infected globally continues to grow at an alarming rate, especially in developing countries. With numbers of infection increasing and the trend towards more people learning about their HIV status earlier, demand for care will mount dramatically in the twenty first century (McNeil et al, 1998). For healthcare providers, the challenge is to provide People Living With HIV/AIDS (PLWHA) with at least a bare minimum of medical and nursing care, as well as psychosocial support.

Individual behaviour is responsible for most HIV transmission, and involves active participation of two people. Transmission can be prevented by a change in the behaviour of either the infected or the non-infected. Sustained behaviour change is one of the main areas to focus in order to bring about a break in transmission (Anyadi 1994).

In the past, HIV/AIDS prevention measures were focused on increasing awareness about modes of transmission, and information on how to avoid becoming infected. However, experience over the past decade has shown that information in itself is insufficient to sustain behaviour change.

The increasing incidence of HIV/AIDS in Ghana, and the cost of hospital care for such persons, give clear indication that there will soon be a time that the government and other health providers will not be able to afford institutional care for PLWHA. Additionally those who are terminally ill generally prefer to die at home with their loved ones (CHAG/UNAIDS, 1998).

The aims and approaches chosen by some HBC programmes depend on the situation and goals. Some of the approaches are:

- To visit people with HIV infection in their houses in order to assess their physical, psychosocial, and spiritual needs, and to provide for these needs.
- To carry out contact tracing.
- To carry out counselling and education within families and communities, provide personal support and promote sustained behaviour change through community counselling.
- Providing basic material assistance to clients when available.
- Providing drugs under medical supervision, and advice on the use of local herbal medicines that may alleviate some of the symptoms of the disease.
- Planning and implementing training programmes for health workers and volunteers.
- Providing adequate support for staff and volunteers both to ensure physical and emotional well being.

The management of HIV/AIDS involves both care and prevention for which an effective frame work is needed, in rural Africa such a framework already exists in the form of an extended family system, even in the urban communities the family retains much of its cohesive power, although weakened to some extent by the spread of modern attitudes and values. In the context of AIDS care and prevention, the family is a national strength; the family is already available and capable of sharing responsibility with the health services for the care of PLWHA.

Primarily AIDS is a sexually transmitted disease, and the key to its prevention is behaviour change. In order to change behaviour, however, people need both information and support, providing these is a task which cannot be left to the health services alone, but requires the active involvement of all available means of communication and social organization (Mouli, 1992).

The support services include the provision of information, care and commodities through governmental, non-governmental and private networks; their efficiency increases as the individuals and communities for which they are intended participate in their design and implementation.

The theme for the 2001 First Regional Community Home Based Care (CHBC) conference in Gaborone Botswana was: "Sharing responsibility for quality care".

In the care of PLWHA all parts of society e.g. community, public and private sectors, non-profit and traditional sectors should share responsibility for the provision of HIV/AIDS care.

Community participation must be strengthened and the role of women, men, and youth recognized, as this is critical to the understanding, establishment, and sustainability of comprehensive HBC and support services. Mann (1992) also argues that the community is the best place for PLWHA to remain and they should be left to stay within the community rather than to be kept in institutionalized care.

There is no affordable cure or vaccine likely to be available in developing countries for a decade or more, the only options are to prevent further spread of the epidemic, minimize its impact and provide a caring and compassionate environment for those infected and affected. The crisis calls for an expanded and intensified response, to mobilize government, civil society, the private sector and the international community to take action, increase resources and build capacity to efforts to slow the spread of the epidemic (Sai, 1999).

Long-term care is an integral part of health and social systems. It includes activities undertaken for people requiring care by informal caregivers (family, friends and neighbours), by formal caregivers (health, social and other workers), and by traditional caregivers and volunteers. The goal of long term care is to ensure that an individual who is not fully capable of long term self care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfillment and respect for that individuals values, preferences and needs, it may be home based or institutional (W.H.O. 2000).

In all W.H.O. regions, there is a great interest in and rapidly growing need for home care, however there is also a danger that the label "Homecare" will be used to justify an abdication of public and government responsibility, an optimal balance between family and public responsibility must be sought (W.H.O. 2000).

Christian Health Association of Ghana, (CHAG) in collaboration with UNAIDS decided to collaborate for an intensified HIV/AIDS response, to the prevention of the disease and Home-Based Care (CHAG/UNAIDS 1997). The Agogo Presbyterian Hospital in the Ashanti Akim North District of the Ashanti Region of Ghana was chosen as one of eleven pilot projects for home-based care for PLWHA in1997, the criteria for choosing Agogo was the high prevalence of HIV/AIDS in the district, a functional HIV/AIDS committee, and a counselling team with a strong and dedicated coordinator. The programme initially involved twenty communities in the district, but was later reduced to eight communities within the Agogo sub district.

This study seeks to describe the HBC programme in the Agogo sub district, to examine community participation in the programme, and its application as a cost effective method in the management of PLWHA, it further seeks to find out the effect of the HBC programme on the lives of PLWHA, and the possibility of using HBC as a tool for sensitizing family members and the community about HIV/AIDS. It is hoped that findings from this study will help in setting up more HBC programmes in other areas of the country, so that PLWHA, through home care will experience the love and support of their communities, and that through the involvement of families and communities, stigmatization and the myths associated with HIV/AIDS will be mitigated.

1.2 THE GLOBAL AIDS SITUATION

In the year 2000, HIV surpassed other pathogens to become the world's leading infectious cause of adult deaths, more than 90% of deaths occur in poor countries, HIV has overtaken the 1918 influenza epidemic as the most devastating communicable cause of adult death since the bubonic plague of the 14th century (Farmer et al, 2001).

In the whole world, heterosexual intercourse has rapidly become the dominant mode of transmission of the virus, although the first reported cases were among homosexuals. Pre-natal transmission is also showing a corresponding increase, transmission through contaminated blood transfusion is gradually being eliminated in most developed countries. In developing countries, steps are being taken to eliminate transfusion-related infections (UNAIDS 2001).

Twenty years after the first clinical evidence of Acquired Immune Deficiency Syndrome was reported, AIDS has become the most devastating disease human kind has been faced with, since the epidemic began, more than 60 million people have been infected with the virus. HIV/AIDS is now the leading cause of death in Sub-Saharan Africa; worldwide it is the fourth biggest killer (UNAIDS, 2001).

As at January 1991, the cumulative total of AIDS cases had increased from 25,000 in 1985 to 460,000 in 1991(GPA, 1991). At the end of 2001, an estimated 40 million people globally were living with HIV. (Refer Table 1.1.). In many parts of the developing world, the majority of new infections occur in young adults, with young women especially vulnerable. About one-third of those currently living with HIV/AIDS are aged 15-24, most of them do not know they carry the virus. Many millions more know nothing or too little about HIV/AIDS to protect themselves against it (UNAIDS, 2001).

1.2.1 GLOBAL RESPONSE TO THE HIV\AIDS PANDEMIC

History was made when the United Nations General Assembly Special Session on HIV/AIDS in June 2002 set in place a framework for national and international accountability in the struggle against the epidemic. Each government pledged to pursue a series of many benchmark targets relating to prevention, care, support and treatment, impact alleviation, and children orphaned and made vulnerable by HIV/AIDS, as part of a comprehensive AIDS response. These targets include the following:

- To reduce HIV infection among 15-24-year-olds by 25% in the most affected countries by 2005 and, globally, by 2010;
- By 2005, to reduce the proportion of infants infected with HIV by 20%, and by 50% by 2010;
- By 2003, to develop national strategies to strengthen health-care systems and address factors affecting the provision of HIV- related drugs, including affordability and pricing. Also, to urgently make every effort to provide the highest attainable standard of treatment for HIV/AIDS, including antiretroviral therapy in a careful and monitored manner to reduce the risk of developing resistance;
- By 2003, to develop and, by 2005, implement national strategies to provide a supportive environment for orphans and children infected and affected by HIV/AIDS;

- By 2003, to have in place strategies that begin to address the factors that make individuals particularly vulnerable to HIV infection, including under-development, economic insecurity, poverty, lack of empowerment of women, lack of education, social exclusion, illiteracy, discrimination, lack of information and/or commodities for self-protection, and all types of sexual exploitation of women, girls and boys;
- By 2003, to develop multicultural strategies to address the impact of the HIV/AIDS epidemic at the individual, family, community and national levels.

Increasingly, other stakeholders, including non-governmental organizations and private companies worldwide, are making clear their determination to boost those efforts.

More companies that are private are also stepping up their efforts. Guiding some of their interventions is a new international code of conduct, on AIDS and the workplace, which was ratified earlier this year by members of the International Labour Organization (the new, eighth cosponsoring organization of UNAIDS).

The challenge now is to build on the new found commitment and convert it into sustained action, both in the countries and the regions hard hit, and in those where the epidemic began latter but is gathering steam (UNAIDS 2001).

1.3 THE SITUATION IN SUB-SAHARAN AFRICA

Currently Africa is said to be at the frontline in the battle against the global AIDS pandemic. AIDS killed 2.3 million African people in 2001.The estimated 3.4 million new HIV infections in sub-Saharan Africa in the past year means that 28.1 million Africans now live with the virus. Without adequate treatment and care, most of them will not survive the next decade. Recent antenatal clinic data show that several parts of southern Africa have now joined Botswana with prevalence rates among pregnant women exceeding 30%. In West Africa, at least five countries are experiencing serious epidemics, with adult HIV prevalence exceeding 5%. However, HIV prevalence among adults continues to fall in Uganda, while there is evidence that prevalence among young people (especially women) is dropping in some parts of the continent (UNAIDS, 2001).

Table1.1. **Regional HIV/AIDS statistics and feature, end of 2001**

	Epidemic started	Adult and children living with HIV/AIDS	Adults and children newly infected with HIV	Adult prevalence rate (*)	% Of HIV-positive adults who are women	Main mode(s) of transmission (#) for adults living with HIV/AIDS
aran	Late'70s early'80s	28.1 million	3.4 million	8.4%	55%	Hetero
Africa e East	Late '80s	440 000	80 000	0.2%	40%	Hetero, IDU
ɛ South- ia	Late '80s	6.1 million	800 000	0.6%	35%	Hetero, IDU
Asia &	Late ' 80s	1 million	270000	0.1%	20%	IDU, hetero, MSM
merica	Late '70s early '80	1.4 million	130 000	0.5%	30%	MSM, IDU, hetero
ean	Late '70s early '80s	420 000	60 000	2.2%	50%	Hetero, MSM,
ı Europe ral Asia	Late '90s	1 million	250 000	0.5%	20%	IDU
n Europe	Late '70s early '80	560,000	30 000	0.3%	25%	MSM, IDU
America	Late '70s early '80s	940,000	45 000	0.6%	20%	MSM, IDU. hetero
lia & 'ealand	Late 70s early '80s	15 000	500	0.1%	10%	MSM
L		40 million	5million	1.2%	48%	

* The proportion of adults (15 to 49 years of age) living with HIV/AIDS in 2001, using 2001 population numbers.

Hetero (Heterosexual transmission), IDU (Transmission through injecting drug use), MSM (Sexual transmission among men who have sex with men).

Source: (UNAIDS, 2001).

1.4 THE HIV/AIDS SITUATION IN GHANA

In 1986 the first 42 cases of HIV/AIDS was first reported in Ghana, this was mainly among women who had travelled outside the country. During the period of March 1986 and September 1988, the reports did not differentiate between HIV and AIDS cases. Now AIDS itself is defined in terms of how much deterioration the immune system has taken place as seen by the presence of opportunistic infections, virtually all infected persons died from the disease.

In Ghana, an individual is said to have developed AIDS when he or she presents with a combination of signs and symptoms, and has a positive HIV antibody test. These are grouped into major and minor signs and symptoms (NACP, 2001).

***The major signs and symptoms include*:**

- Prolonged fever (more than one month).
- Prolonged and chronic diarrhoea (usually over one month).
- Significant weight loss (over a period of time and more than 10% body weight).

The minor signs and symptoms include:

- Persistent cough more than one month;
- Persistent skin infection;
- Aggressive skin cancer (Kaposi Sarcoma);
- Oral thrush (Candidiasis);
- Recurrent shingles (“Ananse”);
- Enlargement of the lymph glands;

An individual with two of these major signs and two of the minor signs is said to have AIDS (National AIDS /STI Control Programme, 2001).

Since the beginning of the epidemic in 1986 up to the end of October 2001, 48,771 estimated cases had been reported (Refer Table1.2) by the Ministry of Health, estimated level of reporting is 30%, the true number of cumulative AIDS cases is not known but according to projections the total was more than 185,000 by 2000 (NACP 2001).

1.4.1 Current estimate of HIV prevalence in Ghana

Results from HIV Sentinel Surveillance System operated by MOH in each of the ten regions indicate that the HIV prevalence among the 15-49 years age old is 3%. While the sentinel data represents that the HIV infection exist in all parts of the country there are important regional differences as shown in Table 1.2. Nearly 70% of reported cases are between 15 – 49 years of age. The peak age for women is 25-29 years and 30 – 34 years for men (NACP, 2001).

1.4.2. Modes of transmission

In Ghana as in the rest of Africa, two transmission mechanisms account for most new HIV infection: heterosexual contact and mother to child transmission (Refer Fig.1.1). The majority of the infection, that is 80% are transmitted through heterosexual contact. Mother-to-child transmission of HIV accounts for approximately 15% of cases. Other modes of transmission are through blood transfusion and contaminated instruments (NACP, 2001).

There is 99% awareness in males and 98% in females in Ghana. Most common sources of information on HIV/AIDS is the radio, other sources include TV, Newspaper, friends and churches. There is however, a low personal risk perception, 58% of adults do not perceive themselves as being at risk (NACP 2001).

Figure 1. HIV TRANSMISSION MECHANISMS IN GHANA

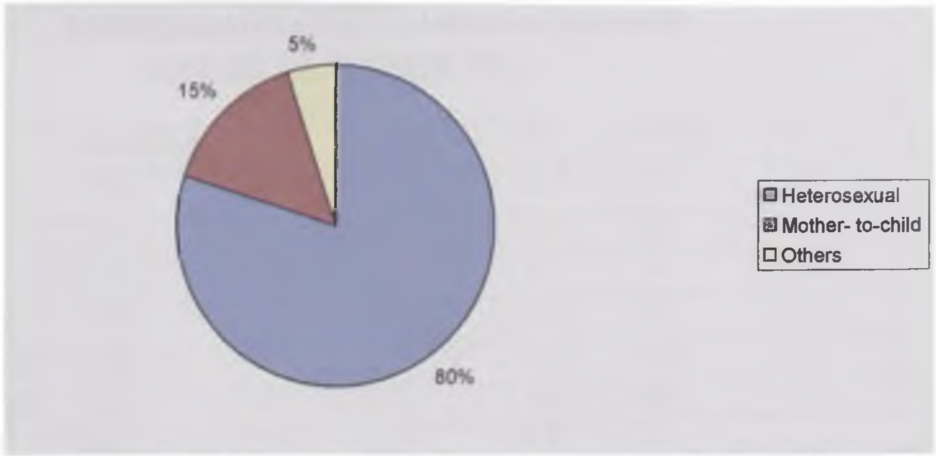


TABLE 1. 2. REPORTED CUMULATIVE AIDS CASES IN GHANA BY REGION MARCH 1986-OCTOBER 2001.

REGION	CASES	%
ASHANTI	14400	29.5
B. AHAFO	3806	7.8
CENTRAL	3139	6.4
EASTERN	7762	16.0
GT. ACCRA	8208	16.8
NORTHERN	2372	4.9
UP. EAST	2318	4.7
UP. WEST	781	1.6
VOLTA	1753	3.6
WESTERN	4146	8.5
UNSTATED	86	0.2
TOTAL	48771	100

Source: National Surveillance Unit. MOH

TABLE 1. 3. REPORTED AIDS CASES IN GHANA BY REGION. JANUARY TO OCTOBER 2001.

REGION	FEMALE	%	MALE	%	TOTAL	%
ASHANTI	794	27.2	583	25.7	1377	26.6
B.AHAFO	159	5.5	107	4.7	266	5.1
CENTRAL	46	1.6	32	1.4	78	1.5
EASTERN	494	16.9	329	14.5	823	15.9
GT.ACCRA	968	33.2	824	36.3	1792	34.6
NORTHERN	255	8.7	228	10.1	483	9.3
UP.EAST	41	1.4	30	1.3	71	1.4
UP.WEST	29	1.0	33	1.5	62	1.2
VOLTA	28	1.0	27	1.2	55	1.1
WESTERN	103	3.5	74	3.3	177	3.4
TOTAL	2917	100.0	2267	100.0	5184	100.0

Source: National Surveillance Unit. MOH.

1.4.3 INTERVENTIONS

There is an international consensus that care and support for those infected with HIV or whose families are affected by AIDS must form an integral part of an AIDS control programme, and that PLWHA must play a key role in all interventions. Different interventions can be adopted to address the transmission mechanism of HIV (NACP, 2001).

Since the major mode of transmission in Ghana is through heterosexual contact, it is especially in this area that interventions have been intensified in Ghana, interventions include:

- Promoting abstinence and faithfulness;
- Reducing the overall number of sexual partners;
- Delaying the onset of sexual activity among adolescents;
- Promoting the use and consistent availability of condoms, including female condoms;
- Strengthening programmes for STD control;

- Encouraging voluntary counseling and testing;

To prevent mother -to-child transmission a pilot project has been launched to test various interventions in Agomanya and Atua in the Eastern region, these ranges from counselling, medical management, and the provision of Niverapine (an antiretroviral drug). Home-based care is also being encouraged (NACP, 2001).

1.5 THE AGOGO SUB DISTRICT

The Agogo Sub-District is the largest of the five sub districts of the Ashanti Akim North district, in the Ashanti Region of Ghana. It is situated in the northern part of the district and covers more than half of the district over an area of 66, 500sq km. It has 65 communities and its capital is Agogo town, is designated as an urban centre. The sub-district has a population of 40,472.

The Agogo Presbyterian Hospital is the first mission Hospital in the Ashanti Region, it was established several years ago in Agogo, the sub district capital. Nine doctors and ninety nurses provide care at the hospital. It has five admission wards, an Out-Patient Department, a Primary Health Care Unit, and a Home-Based Care Programme for People living with HIV/AIDS; patients seen at the Agogo hospital who are symptomatic are tested for HIV/AIDS.

Table 1. 4. **HIV Test results from the Agogo sub district, 1999-2002**

PERIOD	SEX	POSITIVE	TOTAL POSITIVE	NEGATIVE
1999	MALE	98	201	1237
	FEMALE	103		
2000	MALE	51	107	1255
	FEMALE	56		
2001	MALE	55	148	1243
	FEMALE	93		

Source: The Disease Control Unit Agogo Presby Hospital.

1.5.1 Description of the Agogo Home Based Care for HIV/AIDS Patients

The Home-based care HIV/AIDS programme in the Agogo sub district is one of the initial eleven pilot projects started by the Christian Health Association of Ghana (CHAG) and UNAIDS in 1997. As part of its philosophy of providing holistic health care to the people especially the very poor and needy in society, member institutions of CHAG consider HIV/AIDS as a health related priority problem, as part of its activities geared towards reducing the further spread of the HIV and maintaining it at a minimum level, Home-Based Care programmes for PLWHA are on-going in many CHAG institutions in the country (CHAG/UNAIDS 1997).

The HBC team in the Agogo sub district is made up of volunteers from the communities called, "friends of the sick", and health workers, all members of the team are trained HIV/AIDS counsellors .The hospital Chaplain is the coordinator of the HBC programme.

The HBC programme at Agogo has been incorporated into the Primary Health Care programme of the hospital.

Initially, the HBC programme involved twenty communities and covered the whole Ashanti Akim North District; the numbers of communities were reduced to eight after the Presbyterian Church adopted the Agogo sub district.

The volunteers are trained by the health workers to give the PLWHA nursing, psychological and spiritual care, they attend refresher course twice yearly. Monitoring and supervision of volunteers is by the HBC health workers and take place every three months.

The HBC programme in Agogo involves family members in the care of patients; the Kinship system in Ghana provides a good basis for this programme, relatives are taught how to care for patients, the volunteers visit the patients regularly, and HBC health workers visit the volunteers in the communities for updating. The HBC programme is supported by the Presby Church, UNAIDS, Christian Health Association of Ghana (CHAG), and other donors.

1.5.2 Objectives of the AGOGO HBC programme for PLWHA

- To train volunteers to act as counsellors to PLWHA and their families within the communities.
- To educate relatives of PLWHA about HIV/AIDS.
- To assess the physical, psychological, and social needs of PLWHA, and try to meet these needs where possible.
- To educate community and create awareness about HIV/AIDS.
- To give support to PLWHA, and assist them in revealing their positive status to partners and relatives.
- To give medications and nursing care to PLWHA and refer them to hospital where necessary.
- To provide spiritual support, grief and bereavement counselling to PLWHA and their relatives.

1.6 STATEMENT OF THE PROBLEM

The burden of caring for PLWHA places a huge demand on health care systems, health planners are increasingly worried by the financial cost of providing service for PLWHA and the impact this will have on the already stretched health system in terms of finance, health personnel, and time.

Foster (1990) noted that with each death from AIDS, an average of fifteen to twenty years work experiences, related skills, and investment in schooling and training are lost, together with three-quarters of earnings.

Amofa also observed " the importance of the AIDS pandemic in Africa is too frightening to contemplate. Family structures and functions will be threatened as more and more people of the production group are affected and the social and economic cost will mount. For developing countries like Ghana, the most gains achieved in health through Primary Health Care (PHC) stand negated" (Amofa, 1989).

Alternatives to hospital care, including community care, home visiting schemes and self help activities are currently going on in many countries, although for many the initial interest in home-based care has been a way of cutting cost, the benefits extent beyond that.

Involving communities in the care of PLWHA will bring the diseases in the open and confront the myths and prejudices surrounding it (CHAG/ UNAIDS 1987).

1.7 RATIONALE FOR STUDY

In the past, the global strategy against AIDS has focused mainly on prevention; care for HIV-infected people have not been viewed as playing a preventive role in reducing the incidence of the pandemic. People with AIDS have been stigmatized and isolated in many societies, Their abandonment by health care givers will not make them understand the need for prevention and be motivated to protect others. Earlier campaigns created fear, which led to stigmatization of people infected with the virus. The separation between prevention and care could have also been due to inaccurate messages about risk behaviours and modes of transmission. This study seeks to examine the role that home based care plays in creating awareness about HIV/AIDS .

1.8 OBJECTIVES OF STUDY

The main objective of the study is to describe a Home-Based care programme and the extent to which it can be used as an effective tool for information, education and communication on HIV/AIDS.

The specific of objectives are:

1. To determine the Knowledge, attitudes, practices and behaviours of community volunteers, in- family caregivers of people living with HIV/AIDS and families members without HIV/AIDS (FWOPLWA).
2. To examine community participation in the HBC programme.
3. To determine the effect of the HBC programme in the lives of people living with HIV/AIDS.

CHAPTER TWO

LITERATURE REVIEW

2.1 "THE FEAR APPROACH"

In the late part of 1980, there was a dramatic increase in the coverage of the HIV/AIDS pandemic by Governments worldwide. Radio, Television, Newspaper and Posters carried the messages, these media coverage has helped sensitize the public about HIV/AIDS, but its educational impact has been limited. By taking the "fear approach to AIDS education, the mass media may well have contributed to the stigmatization of people with HIV /AIDS.

Because AIDS is perceived as being caused by "messing around with sex before marriage" it is widely regarded as a cause for moral judgment, censure and condemnation, many people with HIV/AIDS fearing rejection by their family, friends, neighbours and workmates, try to conceal their HIV status for as long as possible. Many believe themselves bewitched rather than infected with HIV and seek remedies from traditional healers (William & Tamale, 1991). Increasingly there are reports of people suspected of having AIDS being ostracized by their neighbours, friends, and work mates (Williams 1992).

"On the international level, the WHO now advocates that public education campaigns should move away from the 'fear approach' to AIDS. "

"We want positive campaigning," says Eric Van Praag, chief of Health Care Support Unit of WHO's Global Programme on AIDS. "We want to move away from fear to hope". In February 1989, WHO's Geneva headquarters withdrew its controversial AIDS logo featuring a skull and two hearts which had been criticized by AIDS patients worldwide because of_its vivid association with death (William 1992).

2.2 HOME-BASED CARE: AN ALTERNATE APPROACH

"AIDS is not curable, but it is careable" (Charles Thumi, Kanobangi Community-Based Home Care and Home-Based AIDS Care Programme, Nairobi-Kenya). In 1989, the WHO developed a broad definition of care as a comprehensive, integrated process which recognizes a range of needs for well-being; it includes services and activities providing counselling and psychosocial support, nursing and medical care, legal, financial and practical services (Hubley, 1995).

Since 1987 to date several HBC programmes have sprung up in Africa, most of which provide a variety of services to persons with HIV infection and their families, the programmes are government or non governmental, community-initiated or non-community initiated. Some are hospital based or non-hospital based and or affiliated to various religious bodies.

A HBC programme initiated in Agomanya in the Eastern Region of Ghana has demonstrated that with few extra resources, it is possible to mount a programme of care and support for PLWHA, and start educational and preventive activities on HIV/AIDS within the community (Hampton, 1991). The programme has both health workers and trained volunteers visiting PLWHA at their homes, to administer drugs, and give some education in the form of counselling to family members. They also give social and financial support to PLWHA and their in-family caregivers. Rev. DR. M.M. Mensah who initiated the programme noted that HBC was important to avoid isolation and discrimination against PLWHA and for the education of the community, caring for the sick at home is the only solution, she said:

"If they are in the home among the family, the loneliness of hospitalization is removed. It gives us the chance also to educate the family. We impress on the patients that this is a special disease and therefore dangerous for them to continue engaging in risky activities such as unprotected sex" (Hampton 1991).

Although AIDS is no longer such a taboo subject, many health professionals still view the problem with a mixture of resignation and uncertainty. It is clear that health systems cannot possibly deal with the escalating number of AIDS patients who need medical and nursing care, as well as social, psychological, and material support (William, 1992).

There are considerable benefits in encouraging self-help groups where people with AIDS can meet and provide mutual support, this breaks down the feeling of guilt and isolation that a person with AIDS can feel (Hubley, 1995).

Strategies for diagnosing, counselling, caring for and supporting people with HIV/AIDS, and assisting their families are being encouraged by W.H.O. in all countries. These strategies must take account of local contacts, but they must also build on strengths of the community in particular, and that of the extended family (William, 1992). Most HBC programmes provide a variety of services to persons with HIV infection and their families; these programmes reflect different political, cultural, social, and philosophical concepts. Home Based support is now recognized as the key to decentralizing AIDS care to the greatest strength, which is the family. It also facilitates other health programmes (W.H.O. 1990). The WHO Home Care Handbook 1993 emphasizes the following conclusions, drawn from Home Care initiatives in a variety of countries:

- People who are very sick or dying would often rather stay at home, especially when they know they cannot be cared for in hospitals.
- Being in their own homes and communities comforts sick people, with family and friends close by.

- Home Care means that hospitals are less crowded, so the doctors, nurses and other hospital staff can give better care to those who need to be in hospital.
- It is usually less expensive for families to care for someone at home.
- If the patient is at home, family members can meet their other responsibilities more easily.
- Hospital care is often simply not possible (UNAIDS, 2000).

Providing care and social support for people with HIV/AIDS in the community promotes acceptance of HIV/AIDS as a community problem. An evaluation of The AIDS Support Organization (TASO), a community-based support organization in Uganda revealed that care, defined as medical treatment, counselling and nursing care, helped PLWHA plan their future, practice safer sex, and seek early treatment for infection (MacNeil et al, 1998), TASO provides clinical diagnosis and treatment, referrals for specialist care and counselling, teaches families how to care for PLWHA, makes sure that nutritious food is not lacking, drugs and remedies are available, school fees can be paid, and childcare support is provided.

Care provided by the HBC programme, which does not stop with the clients, helps to stimulate awareness and demonstrates a commitment to non-discrimination against PLWHA, this may in turn lead to a request for more information about the problem.

People who require home based long-term care may also need other services, such as acute physical or mental health care and rehabilitation, together with financial, social, and legal support. Informal caregivers should therefore have access to supportive services including information and assistance in securing help, training, and respite (W.H.O. 2000). The burden of care giving is borne primarily by women, who have little access to, or control of the resources needed to assume this responsibility.

The Salvation Army Hospital at Chikankata in Zambia's Southern Province, has developed a model of AIDS management, which combines home-based care with hospital intervention, Chikankata has also explored the principle of patient care as the starting point for prevention contact tracing, information, education and counselling at the levels of individual, the family and the community (Campbell and William, 1990).

Most African countries have hospitals, which are over-crowded and under-staffed, with health care expenditure growing faster than income, the World Bank in their 1993 World Development Report stated that government hospitals and clinics that account for the greatest part of the modern medical care provided are often inefficient, they suffer from highly centralized decision making and under budgetary allocations. It noted that the critical and cost effective interventions are best delivered at lowest level facilities (World Bank Report, 1993).

The Copper belt Health Education Project in Zambia aims at informing, training, motivating and supporting groups of caregivers and opinion leaders, who because of their professional status, can act as "gatekeepers" to large sections of the general public, as well as communicating information about HIV/AIDS. Many members of these groups are also well placed to provide social, psychological, or spiritual support needed to motivate people to practice safer sexual behaviour. The caregivers are, Health workers, traditional healers, religious leaders, teachers, journalist, formal sector workers, and political leaders (Mouli, 1992). Home care has an advantage over hospital care, it enables the counsellors to assess the client's social and economic situation, it helps to break down or prevent the sense of isolation experienced by many PLWHA. Home care brings the counsellor into contact with other members of the client's family (Hampton, 1990).

In a study done in 1994 on HBC programme in the Berekum District of the Brong Ahafo Region in Ghana, it was obvious that if family members are made to care for PLWHA, not only will they alleviate the burden of the already stretched health facilities but will greatly facilitate a change in belief about HIV/ AIDS, create a positive attitude towards PLWHA, and could be a stepping stone towards a supporting environment. This would be a move from creating awareness, to sustain behaviour change towards the "crashing down" of this deadly disease (Anyadi, 1994).

Sister Margaret Moham of the Holy Family Hospital initiated the home-based care programme in June 1990, it was felt at that time that the only way to achieve reasonable management of AIDS patients was to involve family members in their care; family care is well documented in the Ghanaian culture, illness affects not only the person who is ill but also the whole family; family members are taught how to care for PLWHA. The HBC programme for PLWHA at the Berekum Holy Family Hospital has been described as a programme that provides regular visits to check on patients, provide some medication, counselling and information for PLWHA and their families (Anyadi, 1994).

In all W.H.O. regions, there is great interest in, and rapidly growing for home care. However, there is also a danger that the label "Home Care" will be used to justify the abdication of public and government responsibility. This will have dire consequences for quality of care, for families and in particular for health and lives of women who are the main caregivers both for their own families, communities and within the formal health sector (W.H.O. 2000).

2.3 Community Participation

Community participation refers to the education and empowering process in which people in participation with those able to help them, identify problems and needs, and increasingly assume responsibility for planning, managing, controlling and assessing the collective action that needs to be taken.

Communities have large been recognized as important stakeholders in health, but their role until the last decade or two have not been clearly defined, (Tetteh and Asibuo, 1998).

A W.H.O. study group in 1991 interpreted community participation in three different ways as contribution, organization, and empowerment.

To date, very few development sectors have done much to further an understanding of community participation with the view the of strengthening it, however the Ministry of health in Ghana reinforced the crucial role that communities play as stakeholders by preparing a position paper on community participation on health. The result is that there is a greater emphasis on providing communities with skills, leadership, and general health awareness that they need in order to play an active role in health development. The definition of community participation as stated in the position paper is:

"The process of initiation and sustaining dialogue with various members of a particular community in a structured manner with the view to genuinely consulting them as equals in a programme of activities that aim at building a team between programme managers and community members to jointly understand health problems in the community, to find common solutions to such problems and to act together to solve these problems, using as much human and material resource as possible from the community".

The document explained the purpose of community participation as:

- Increase access to services;
- Improve in quality of care;
- Improve in the efficient use of resources;
- Empowering communities;
- Ensuring cost sharing;
- Facilitate inter-sectoral collaboration;

The strategies for achieving the above include:

- Community mobilization;
- Promotion of participatory health education and information facilities;
- Manage community based institutions;

Studies done on the Ejisu-Juaben Child survival and development project and the Navrongo Community health and family planning project by Tetteh and Asibuo indicated that, an important factor which hinders community participation in health service delivery and other health related programmes is thought to be the lack of involvement of communities from the very onset of new health projects, therefore, involving the community in the design and implementation of the projects is crucial in stimulating not only their interest, but also facilitating the success of the project(Tetteh and Asibuo, 1998).

Justification for community participation comes from a variety of sources including lessons learned from the failures of conventional "top down " educational programmes as well as the achievements of community based programmes, an important justification for community participation is the need to shift the emphasis from individual to the community. Many influences on behaviour at the community level are under the control of individuals, these include social pressure from other people through norms, shared culture and local socio-economic situations, even if the influence is at the national level, it is often through pressure from communities that government will change (Hubley, 1993).

A major problem in the development of health services is the gap between the decision makers and community, the community is much more likely to become involved in a programme and take up services if the community is involved in the choosing of priorities and deciding on plans, because they are seen to meeting their needs. The enthusiasm that comes from community participation can lead to a greater sense of self-reliance for the future. Community participation also leads to a better relationship between community and health workers instead of servant – master relationship; there must be trust and partnership (Hubley, 1993).

2.4 THEORIES

Human behaviour plays an important role in the prevention, care, treatment and rehabilitation process of most health problems, however the influences on a person's behaviour may be their control at family, community, district, national or even international level (Hubley, 1993). Understanding of human behaviour requires complex, multiple and abstract concepts which are used as tools to predict health related behaviour.

For the development of a successful HIV/AIDS prevention programme it is essential to understand the determinants of intentions to engage in risk-related and prevention behaviour. Social and behavioural science theories aim at identifying and helping us understand the elements that affect seemingly diverse classes of behaviour and how these elements function. They may also suggest or actually offer ideas on how we can influence such elements under a variety of circumstances and they furnish us with valuable tools for solving a wide range of problems. (Anyadi 1994).

Social and behaviour sciences theories can be regarded as being essentially statements identifying factors that are likely to produce particular results under specified conditions. These theories can be used as guides in selecting, developing, or applying the most promising strategies and methods for solving a particular problem.

The Health Belief Model (HBM)

The HBM model is a psychological model that attempts to explain people's behaviour by focusing on attitudes, and beliefs of individuals. HBM was developed in the United States of America to explain the lack of public participation in health screening programmes. Since then, it has been used to explore a variety of health behaviours, including sexual risk behaviour and HIV/ AIDS.

The key variables in the HBM are:

- **Perceived threat** – This consists of two parts:

  -Perceived susceptibility i.e. one's subjective perception of the risk of contracting a health condition.

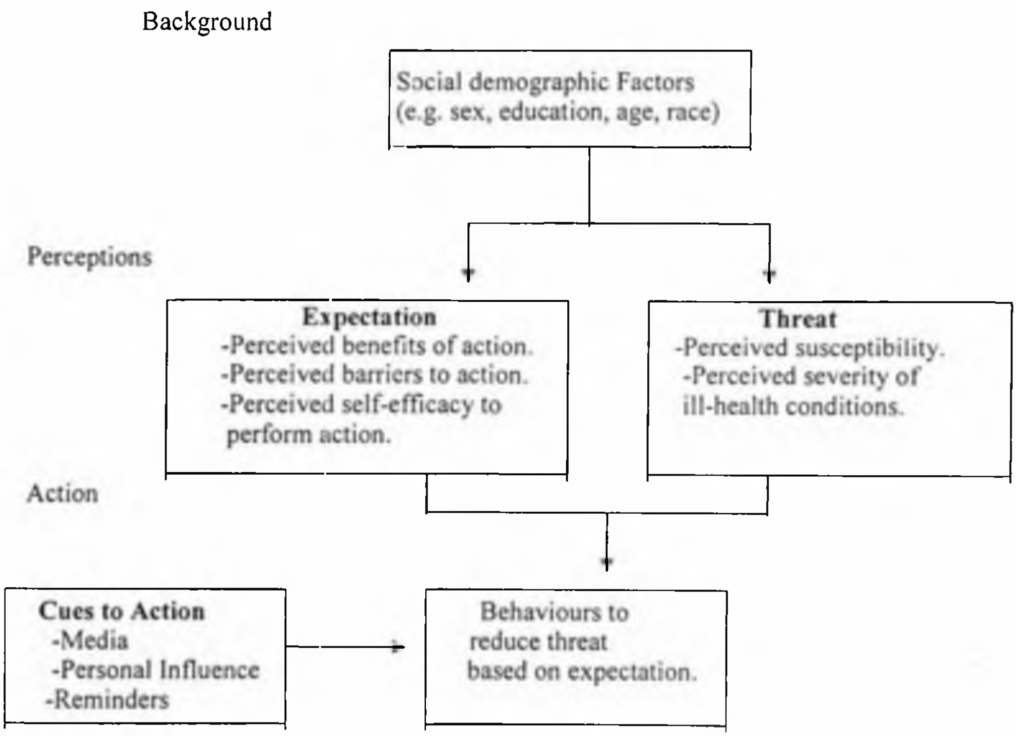
  -Perceived Severity, this is one's feeling concerning the seriousness of contracting an illness.

- **Perceived Benefits**: The Believed effectiveness of strategies designed to reduce the threat of illness.
- **Perceived Barriers**: The potential negative consequences that may result from taking particular health actions, including physical, psychological, and financial demands.
- **Cues to Action**: Events, either bodily (e.g. physical symptoms of a health condition) or environmental (e.g., media publicity) that motivate people to take action. Cues to actions are an aspect of the HBM that has not been systematically studied.

- Other Variables: Diverse demographic, sociopsychological, and structural variables that affect an individual's perceptions and thus indirectly influence health-related behaviour.
- Self-Efficacy: The belief in being able to successfully execute the behaviour required to produce the desired outcomes.

This model has been used to explore a variety of health behaviours in diverse populations. With the advent of HIV/AIDS, the model has been used to gain a better understanding of sexual risk behaviours.

Fig.2.1 The Health Belief Model



Theory of Reasoned Action (TRA)

Research using the TRA has been used to explain a variety of human behaviours since 1967. This theory is based on the premise that humans are rational and that the behaviours being explored are under volitional control, the theory provides a construct that links individual beliefs, attitudes, intentions, and behaviour .

The theory variables are:

- **Behaviour:** A specific behaviour defined by a combination of four components: action, target, context, and time (e.g., implementing a sexual HIV risk reduction strategy (action) by using condoms with commercial sex workers (target) in brothels (context) every time (time).
- **Intentions:** The intent to perform behaviour is the best predictor that a desired behaviour will actually occur. In order to measure it accurately and effectively, intent should be defined using the same components used to define behaviour: action, target, context, and time. Both attitude and norms, influence one's intention to perform behaviour.

The behavioural and normative beliefs (Cognitive Structures) influence individual attitudes and subjective norms respectively. In turn, attitudes and norms shape a person's intention to perform behaviour, the authors of the TRA argue a person's intention remains the best indicator that the denied behaviour will occur. Overall, the TRA model supports a linear process in which changes in an individual behaviours and normative beliefs will ultimately affect the individual's behaviour. The attitudes, norm variables, and their underlying cognitive structures, often exert different degrees of influence over a person's intention.

Results from a study of northern Thai revealed that male men's perception of peer norms were best predictor of condom use.

Yet in a study of college females in the United States, attitudinal beliefs exerted greater influence on the intent to use condoms by sexually inexperienced females.

Studies conducted in Zimbabwe applied the theory to research condom usage by females and males. Other study populations for TRA HIV/AIDs research included women, STD clinic patients, female commercial sex workers, men who have sex with men, college students (Denison, 2000).

Innovative Diffusion Theory

This theory has great relevance for community-based programmes. Its key component is community organization. The theory argues that whilst the mass media are effective in creating knowledge of innovations, interpersonal channels are more effective in actually changing attitudes and behaviours, it classified people as: innovators, early adapters, early majority, late majority or late adapters.

Community organization, mobilization of resources and rapid diffusion require a good understanding of the needs and aspirations of the target community.

CHAPTER THREE

THE STUDY DESIGN

This chapter presents the methodology and the limitation of the study.

3.0 METHODOLOGY

3.1. STUDY DESIGN

The research design for this study was descriptive in nature using both qualitative and quantitative methods to elicit information on the HBC programme, and its effect on community members. Participants in the focus group discussion and semi-structured interviews were recruited from the communities; field interviewers were recruited from the PHC team.

3.2 THE SETTING

The research took place in the Agogo sub-district, it's capital is Agogo, which is linked by a reliable road to the district capital, Konongo. Most of the road networks in the sub-district are almost inaccessible in the rainy season. The people are subsistence farmers and plant mainly plantain, tomatoes cassava, and cocoyam; there are a few commercial farmers in the sub district growing mainly cocoa.

Health Facilities in the Sub district:

- Agogo hospital – Presby Church;
- Ananekrom Health Center – Ministry Of Health (MOH);
- Bebome Health Center –MOH;
- Three private clinics;
- One private maternity home;

The Agogo Presbyterian hospital serves the whole Ashanti Akim North District.

The number of HIV/AIDS cases in the sub district is high, with 201 cases recorded in 1999, 107 cases in 2000 and 148 cases in 2001.The HBC programme for PLWHA was set up five years ago and eight communities are involved in the programme, the communities are: Akutuase, Pekyerekye, Obenemase, Agogo, Hwidiem, Domeabra , Wiawso and Nyampenase. The HBC team is made up of nine health workers and twenty-seven community volunteers, the HBC coordinator is the Chaplain of the Agogo hospital.

3.3 SAMPLE

3.3.1 The Study Population:

- All People living with HIV/AIDS (PLWHA) in the in the eight communities;
- All In-family caregivers of AIDS patients (dead or still living) in the eight communities;
- All Families members without AIDS (FWOPWLA) in the eight communities;

3.3.2 Sampling Method:

A purposive sampling technique was used in this study, due to the sensitivity of the topic and the stigma attached to HIV/AIDS in the area, it was difficult for people to give out information. Using the list from the HBC register all PLWHA involved in the HBC programme were contacted and those willing to take part in the study were recruited.

HBC health workers contacted in- family caregivers of AIDS patients (dead and alive) and those willing to take part in the study were recruited.

All twenty-seven HBC community volunteers were recruited into study.

Opinion leaders identified family members without AIDS and they were contacted, those above twenty years of age, and willing to participate were recruited into the study. All together sixty-five participants were recruited into the survey, and the focus group discussions were made up of thirty-two participants.

In spite of the bias that this group constituted, the nature of the study was such that this could not be avoided.

3.4 DATA COLLECTION

Consent was obtained from the District Director of Health Services, and authorities of the Agogo hospital for the study.

3.5 TRAINING

The training involved a research team made up of:

- Two research assistants;
- Moderator of the Focus group discussions and In-depth interviews (IDI);
- Note taker during the FGD, and IDI;
- Three interviewers for the semi-structured questionnaire;

The training lasted for two days, and was conducted by the main investigator. A work plan was drawn up during the training, and special emphasis was laid on these issues:

- Preventing vocal respondents from dominating discussions;
- Encouraging quiet participants to respond;
- Steering conversation back to main topic if conversation is deviating from topic;

- Explaining purpose of interview to respondents and reassuring participants about confidentiality;
- Location of interview and discussion were conducive for spontaneous responses;

3.6 PRETESTING

The research tools were pre-tested at Magyeda one of the communities in the Agogo sub-district not involved in the HBC programme. Changes were made after the pre-testing, some the questions were rephrased so as to shorten questions or prevent ambiguity.

3.7 DATA COLLECTION, TECHNIQUES AND TOOLS

The data collection technique used for this study was focus group discussion, semi structured interviews, and in-depth interviews.

A focus group discussion guide, an in-depth interview guide, and a semi-structured questionnaire were the data collection tools used in the study.

3.7.1 Focus Group Discussion

Focus group discussions with in-family caregivers of PLWHA, HBC community volunteers, and family members without AIDS (FWOPWLA) were held at the in-service training center of the Agogo Presbyterian hospital. The recording technique was tape recording and note taking. The tape recording was to make up for any information that might have been missed by the note taker. The notes would also be available should there be any problem with the recording. Each focus group discussion lasted for an hour and a half; there were refreshments after each session to allow interaction between researcher and participants.

3.7.2 In-Depth Interviews

In-depth interviews were held to elicit the effect of the HBC programme on the lives of PLWHA, and community participation in the HBC programme. Interviews were held at various locations selected by the PLWHA, each PLWHA was asked to select a place for interview where he/she would feel comfortable and have maximum privacy, one chose to be interviewed at the hospital chapel, whilst another chose to be interviewed under a tree near her house. The HBC programme/PHC coordinators were interviewed at their respective offices. Opinion leaders were invited to the hospital hall to be interviewed.

3.7.3 Semi Structured Interviews

Trained interviewers administered the semi-structured questionnaires; each interview lasted for approximately thirty minutes, Community volunteers, in-family caregivers, FWOPWLA were invited to the conference hall of the Agogo hospital on different days for interview.

3.8 DATA STORAGE AND ANALYSIS

Analysis commenced with the transcription of FGD tapes in order to provide meaningful analysis. Categories of themes were identified and elements in each category were coded and stored in computer. Epilnfo was used for analysis.

3.9 ETHICAL CONSIDERATION

A letter was written to the authorities of the DHMT and the Agogo Hospital authorities to obtain permission for study.

The study was explained to each participates to obtain verbal consent (due to high illiteracy rate among respondents).

To prevent stigmatization of PLWHA, other chronically ill patients were recruited into study.

The members of the HBC team who are known as "friends of the sick" were used in recruiting of participants for the study and for data collection.

Reassurance was given to respondents by explaining that no names would be disclosed, and that after transcribing and analysis of interviews and discussions, the recordings would be erased.

Participants were assured that all information will be kept confidential.

People's right not to participate in study or opt out was respected.

3.10 LIMITATIONS OF STUDY

The results of this study cannot he generalized due to the sampling procedure used. The sample may be quite unrepresentative of the population under study, it was however not possible to adjust for this.

CHAPTER FOUR

RESULTS

In this chapter the results of the research is analyzed and presented in descriptive, graphical, and tabular forms.

Thirty-two participants formed the FGD group:

- Ten In-family care givers of PLWHA;
- Twelve family members without AIDS (FWOPWLA);
- Ten HBC community volunteers;

The KABP survey involved sixty-five respondents, made up of in-family caregivers, HBC community volunteers, and family members without HIV/AIDS.

In-depth interviews were held with the HBC and PHC coordinators, two PLWHA, and opinion leaders.

In-depth interviews were held with opinion leaders, the coordinators of the HBC programme and people living with HIV/AIDS to elicit information about the HBC programme.

4.1 DEMOGRAPHIC CHARACTERISTICS OF RESPONDENTS

TABLE 4.1

	*FGD**		SSQ*	
# OF PARTICIPANTS	32		65	
SEX				
MALES	21	(67%)	36	(55%)
FEMALES	11	(33%)	29	(45%)
AGE				
BELOW 25 YRS	4	(12%)	11	(17%)
BETWEEN 25-60 YRS	23	(71%)	45	(69%)
OVER 60 YRS	5	(17%)	9	(14%)
MARITAL STATUS				
MARRIED	22	(68%)	41	(63%)
SINGLE	5	(15%)	17	(26%)
DIVORCED	4	(14%)	2	(3%)
WIDOWED	1	(3%)	5	(8%)
NUMBER OF CHILDREN				
LESS THAN 3 CHN	7	(20%)	11	(17%)
BETWEEN 3-6 CHN	20	(63%)	44	(68%)
MORE THAN 6 CHN	2	(7%)	7	(10%)
NO CHN	3	(10%)	3	(5%)
EDUCATION				
NO EDUCATION	7	(20%)	15	(23%)
PRIM / MIDD/ JSS	14	(44%)	38	(58%)
SEC / POST SEC	11	(36%)	12	(19%)
RELIGION				
CHRISTIANS	21	(66%)	54	(83%)
MOSLEMS	5	(16%)	8	(12%)
OTHER RELIGIONS	6	(18%)	3	(5%)
OCCUPATION				
FARMERS	22	(70%)	41	(63%)
OTHEROCCUPATIONS	10	(30%)	24	(32%)
ETHNICITY				
AKANS	29	(90%)	52	(80%)
OTHER TRIBES	3	(10%)	13	(20%)

*FGD** FOCUS GROUP DISCUSSION
*SSQ** SEMI STRUCTURED QUESTIONNAIRE
CHN: CHILDREN.

In the analysis the major categories of information that emerged were:

- Source of Information about HIV/ AIDS;
- Knowledge and preventive of AIDS;

- Attitudes about HIV/AIDS;
- Sexual practices and Behaviour change;
- How respondents felt about HBC;
- Miscellaneous issues raised by respondents;

4.2 SOURCE OF INFORMATION ABOUT HIV/AIDS

FOCUS GROUP DISCUSSION

4.2.1 Community Volunteers

Community Volunteers gave their main source of information as:

- Radio;
- Newspapers;
- Posters;
- Church/mosque;
- Hospital;
- Television;
- Film shows;
- Role-Plays by different groups;
- HBC volunteer training;

One respondent said:

"Initially people thought it was a spiritual illness, but the film on AIDS shown to the community has really given credibility to the existence of HIV disease."

Overall, the volunteers mentioned the film shows on AIDS and HBC training as their credible source of information on AIDS.

4.2.2 In- family caregivers of PLWHA

The caregivers gave their source of information about HIV/AIDS as:

- Talk by health workers

- Radio
- Church
- T.V

A respondent said; "*We have health talks at church often, we invite health workers to give us the talk on AIDS*"

Most caregivers mentioned the church as their most credible source of information, followed by education and information from the home- based care health workers.

4.2.3 Family members without AIDS (FWOPWLA)

Respondents gave sources of information on HIV/AIDS as:

- Radio;
- Newspapers;
- Posters;
- Church;
- Hospital;
- Videocassettes;
- HBC volunteers;

Most respondents in this group gave their credible source as the Church, their reason being that, at church there is more in-depth interaction with the presenters, with a period of question time.

A respondent explained that:

"During *the church forum, issues on AIDS were explained to us in simple ways, that we understood the full implications of the disease*"

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Figure 4.1 Results of Semi Structured Questionnaire on source of information on HIV/AIDS

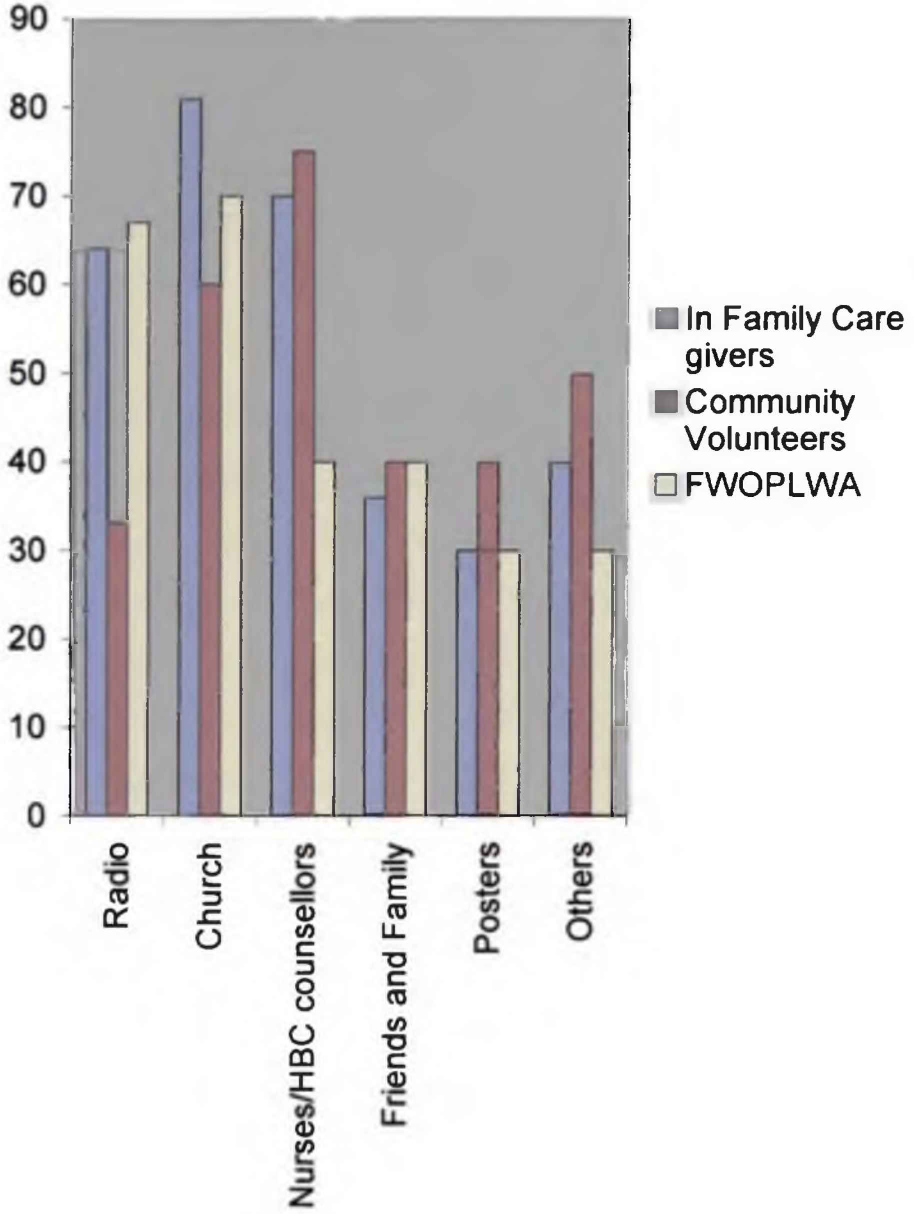

Table 4.2 Source of Information on HIV /AIDS

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total. No of Respondents	22		20		23	
Source of Information	No	%	No	%	No	%
Radio	14	64	7	33	15	67
Church	19	81	12	60	16	70
Nurses/HBC consellors	15	70	15	75	9	40
Friends/Family	8	36	8	40	9	40
Posters	7	30	8	40	7	30
Others	9	40	10	50	7	30

4.3 KNOWLEDGE ABOUT HIV/ AIDS

FOCUS GROUP DISCUSSION

The elements that made up this category identified the knowledge level of the respondents about HIV/AIDS. This varied from cause, modes of transmission, signs and symptoms, prevention, link of HIV/AIDS to STIs, treatments of HIV/AIDS and cure.

The respondent's knowledge about HIV/AIDS was good in all the Focus Group Discussions. Most respondents were able to give modes of transmission, signs, and symptoms, and the fact that AIDS had no cure.

4.3.1 Community Volunteers

Most volunteers mentioned a virus as the cause of AIDS, one volunteer said:

"*AIDS is a disease that kills a lot, when you get AIDS you have boils, skin rashes, diarrhoea, it is a serious disease and caused by a germ in the blood.*"

Volunteers were able to identify all the different ways of transmission of HIV/AIDS.

One respondent summarized the transmission as:

"The source of infection is sexual intercourse, sharing blades and transfusion of blood",

A third volunteer gave a mode of transmission as, " *A baby whose parents are HIV Positive can get AIDS through child birth*".

On AIDS prevention most volunteers mentioned intensification of HIV/AIDS campaign programmes as the best way to prevent HIV/AIDS, they also talked about faithfulness to partner, abstinence and condom use, they all agreed that teaching the youth to be God fearing could help them abstain from sex.

A volunteer said:

"*We should teach our children the fear of God; if a person fears God he will lead a God fearing life and will not get AIDS*"

Some volunteers were able to tell the link between STIs and HIV/AIDS, most of them gave the link as both being sexually transmitted, one gave the link as people with STD having a greater chance of getting HIV/AIDS:

Most volunteers were able to give all the signs and symptoms of AIDS, they mentioned boils, skin rashes, diarrhoea, weight loss, cough, and fever on and off as the main signs and symptoms.

They all agreed that there was no cure for AIDS.

To the question of who is at risk of getting AIDS, most volunteers said everybody can get AIDS, but a few volunteers responded that only those who engage in sexual promiscuity were at risk of getting HIV/AIDS; some also mentioned people who engage in unprotected sex as being at risk of getting AIDS.

4.3.2 In-Family Caregivers of PLWHA

All caregivers were able to give the cause of AIDS as a germ in the blood.

On the mode of transmission of HIV/AIDS, the responses ranged from sexual intercourse, sharing of blades and needles, to spiritual means,

One caregiver gave the cause as:

"*Warzam during circumcision, or transfusion of infected blood*"

As was expected all the caregivers knew the signs and symptoms of AIDS, they mentioned weight loss, boils, shingles, skin rashes, and vomiting as some of the signs and symptoms.

On prevention of AIDS, respondents mentioned health campaigns, faithfulness to partner, and the fear of God as ways of preventing HIV/AIDS.

All caregivers said there was no cure for AIDS, although one caregiver's response was: "*I have heard that pregnant women can be protected with drugs so that their babies don't get infected*"

To the question of who is at risk of getting HIV/AIDS, the response from caregivers ranged from young people, unfaithful spouses, and prostitutes, to women who flirt around.

A respondent said: " *Women who flirt around and prostitutes, they can also infect their husbands*"

4.3.3 Family members without AIDS

Most respondents in this group knew the cause of AIDS as a germ in the blood.

A respondent said, " *Germs that we cannot see causes AIDS*".

On the modes of transmission of HIV/AIDS, respondents were able to give all the different modes of transmission except Mother- to –Child transmission.

The respondents gave the signs and symptoms as weight loss and diarrhoea.

Most respondents talked about health campaigns, use of condoms, and faithfulness to partners and taking only one wife as ways to prevent HIV/AIDS.

On the issue of the link between HIV and STIs, respondents said there was no link.

A respondent said:

" They are different, STIs don't kill, STIs have existed for a long time, AIDS is a new disease, it has no cure, and STIs are treatable."

When the question of who is at risk of getting AIDS was asked, respondents in this group responded that it was mainly prostitutes; people who were sexually promiscuous and people who don't take good care of themselves who were at risk of getting AIDS.

Most community volunteers believed everybody could get AIDS, whilst majority caregivers and FWOPLWA said that prostitutes and unfaithful spouses were those at risk.

4.4 RESULTS OF THE SEMI STRUCTURED QUESTIONNAIRE ON KNOWLEDGE

Table 4.3 Knowledge about causes of AIDS

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Causes	No	%	No	%	No	%
Virus/Germ	18	82	19	96	16	70
Other Causes	2	9	1	4	1	4
Don't Know	2	9	0	0	6	26

Figure4.2 Results of Semi Structured Questionnaire on Knowledge about Causes of HIV/AIDS

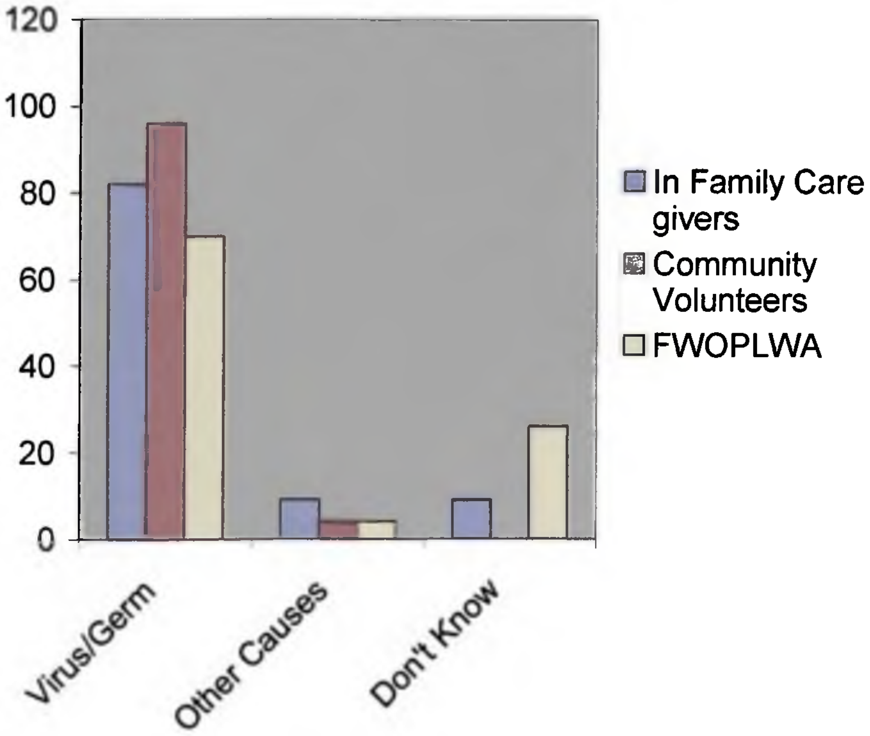

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Table 4.4 **Knowledge about modes of transmission**

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Modes of Transmission	No	%	No	%	No	%
Sexual Intercourse	22	100	19	98	23	100
Contaminated Instruments	10	45	6	30	5	21
Blood Transfusion	4	18	8	40	7	30
Mother To Child	0	0	1	1	0	0

Figure4.3 Results of semi Structured Questionnaire on Knowledge about modes of transmission of HIV/AIDS

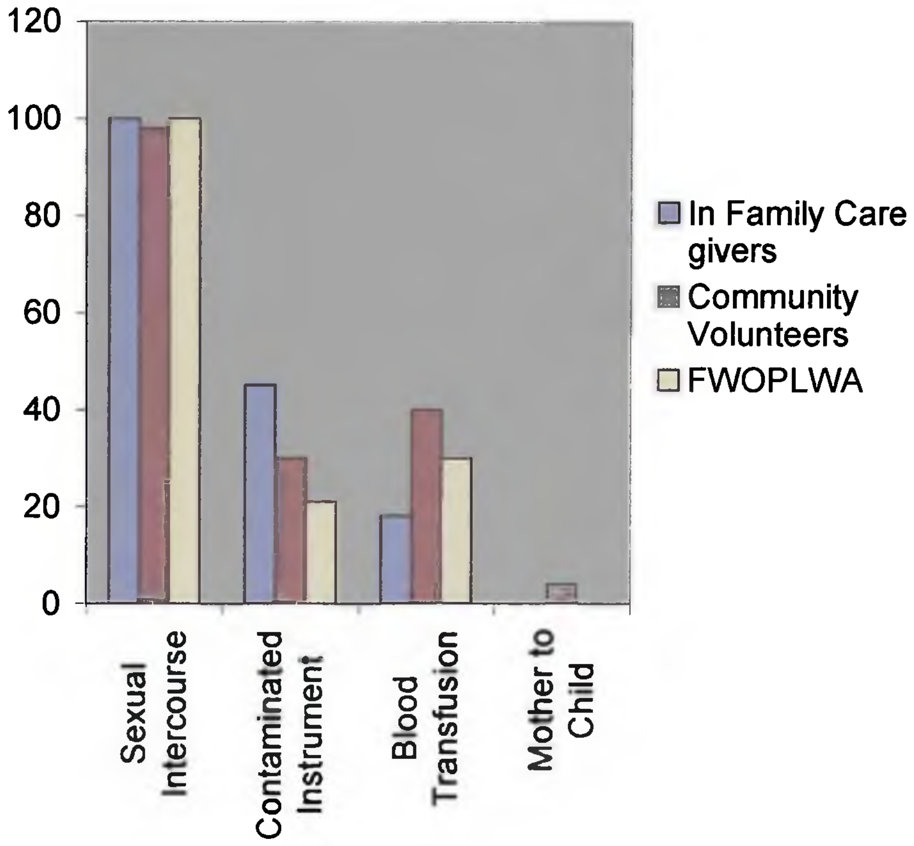


Table 4.5 Being at Risk

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
People at risk	No	%	No	%	No	%
Everybody	16	73	18	92	21	91
Prostitutes	6	27	1	5	1	3
Multiple sexual partners	0	0	1	5	0	0
Youth	0	0	0	0	2	7

FIGURE4.4 Results of Semi Structured Questionnaire on being at risk

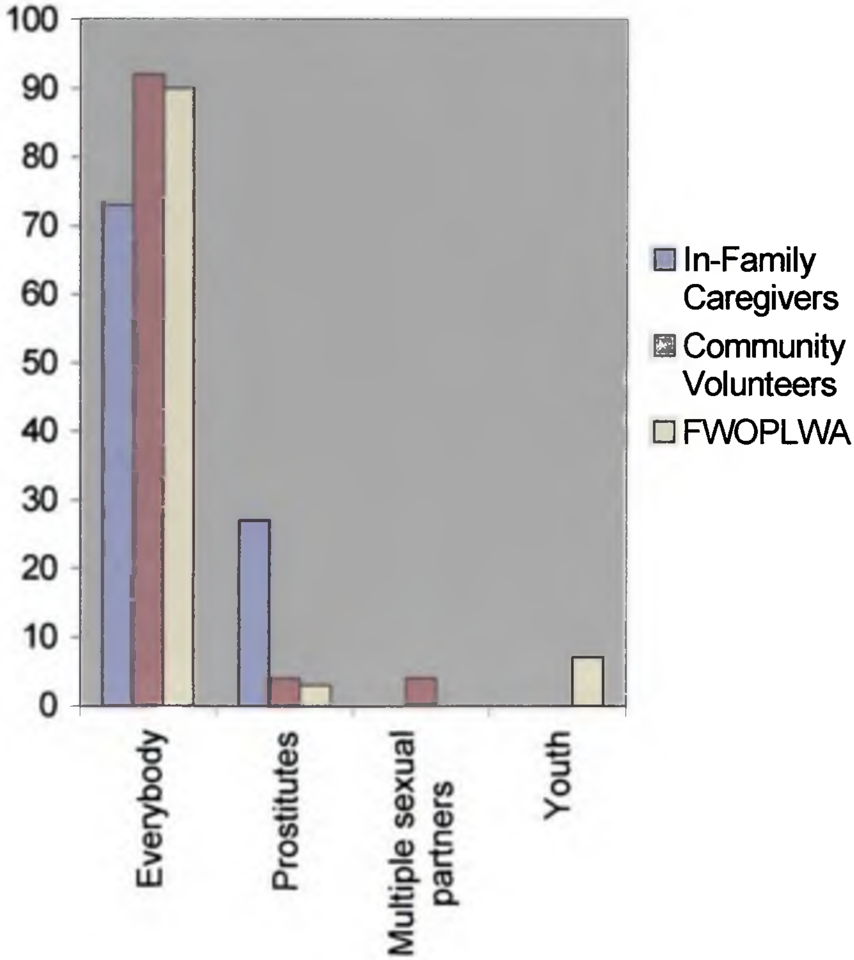


Table 4.6 **Knowledge about Cure for AIDS**

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Cure for AIDS	No	%	No	%	No	%
No Cure	22	100	20	100	22	97
Cure	0	0	0	0	0	0
Don't Know	0	0	0	0	1	3

Figure 4.5 **Knowledge about cure for AIDS**

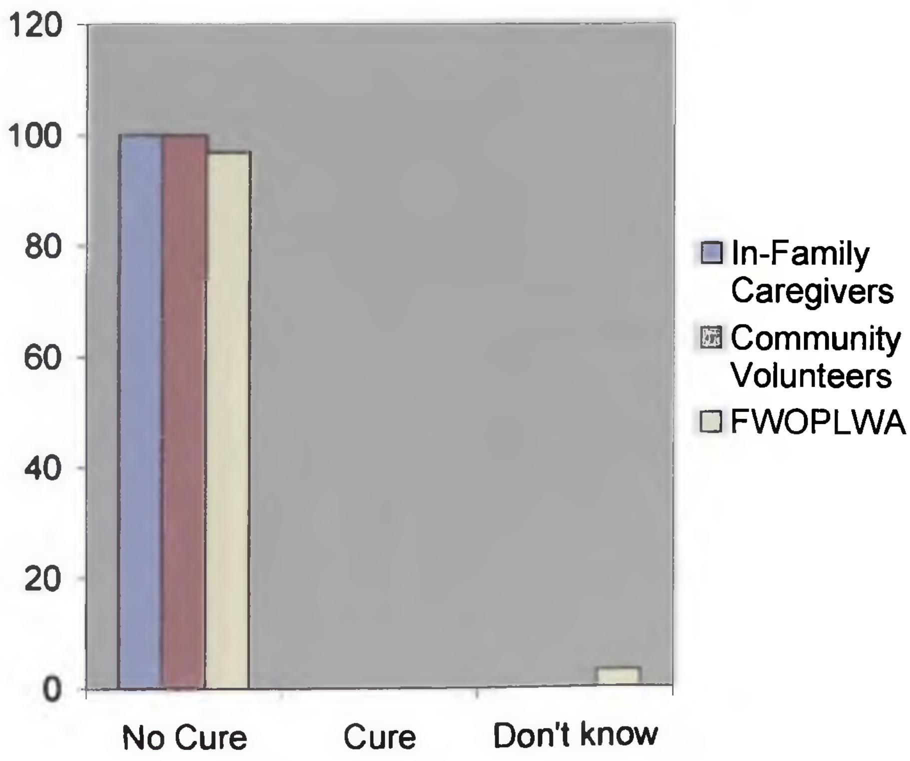
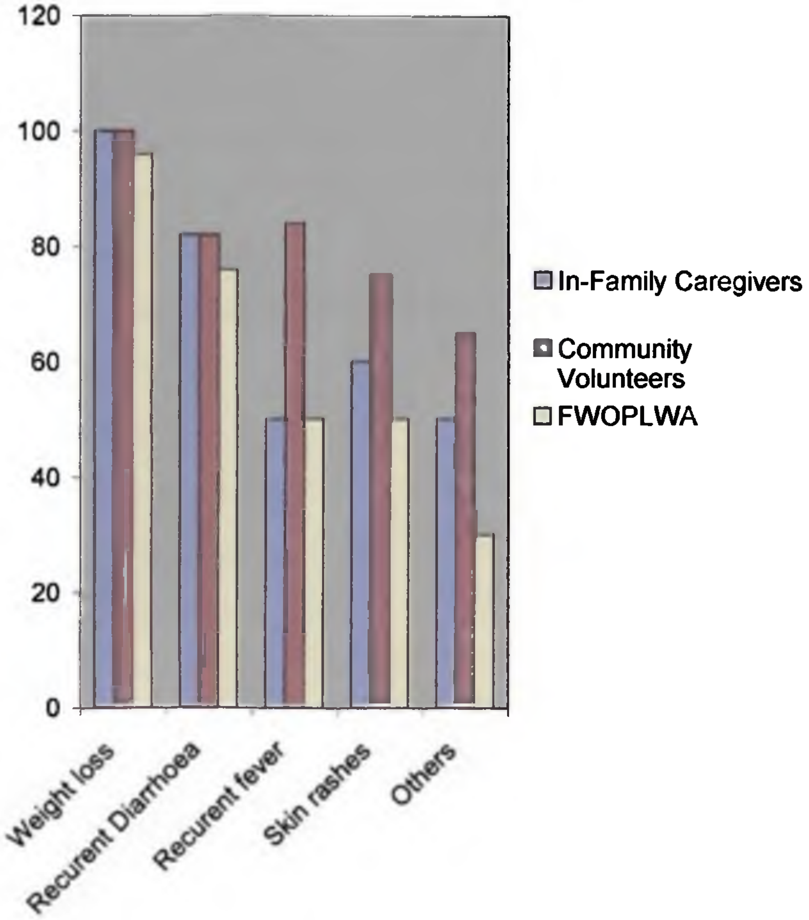


Table 4.7 Knowledge about Signs and Symptoms

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Signs and symptoms	No	%	No	%	No	%
Weight Loss	22	100	20	100	22	96
Recurrent Diarrhoea	18	82	16	80	17	76
Recurrent Fever	11	50	17	85	12	52
Skin Rashes	13	60	15	75	12	52
Others	11	50	13	65	7	30

Figure4.6 Results of Semi Structured Questionnaire on Knowledge about signs and symptoms of AIDS



4.5 ATTITUDES ABOUT HIV/AIDS

Respondents' variables were derived from the following measures:

- If they had ever seen a person with AIDS;
- Feeling towards PLWHA, and the way they will relate to a PLWHA;
- How embarrassed they will be if a family member gets HIV/AIDS;
- Views on isolation of PLWHA;
- Responsibility for the care of PLWHA;

4.5.1 Community Volunteers

All community volunteers had seen a person with AIDS, and they all had a positive attitude about HIV/AIDS and PLWHA, most of them empathized with PLWHA and indicated that they did not feel threatened by their illness, and would relate to them the way they would with any sick person.

A volunteer said:

"*Initially we used to shun PLWHA, because we were scared, but since we became volunteers we visit them, care for them and comfort them*"

Most HBC community Volunteers agreed that a family member with AIDS brings shame and disgrace to the family, they also said death from AIDS was a shameful death.

A volunteer said:

"*Death from AIDS is a disgraceful death, because of the way the person looses weight, recently some children were fighting and one said to the other, shame on you, didn't your mother die from AIDS? AIDS death is disgraceful*"

On isolation of PLWA:

With the training given to the volunteers, one would have thought that all of the volunteers would say that PLWHA should not be isolated, but some volunteers said they should be isolated.

A volunteer said:

"If the person has diarrhoea he must be isolated, but volunteers and relatives should go there and care for them."

The reasons that some volunteers gave for wanting PLWHA be isolated was that, isolation would be a deterrent to other people not to be sexually promiscuous, and another is the possibility of the PLWHA knowingly infecting others.

The volunteers who were against isolation, felt isolation will be a punishment, and will lead to the early death of PLWHA.

4.5.2 Caregivers of PLWHA

All caregivers had positive attitudes towards people with AIDS, they had all seen PLWHA, cared for them and seen some die.

When In-family caregivers were asked about their feeling for PLWHA and how they would relate to them, most of them said they felt sorry for PLWHA, and would relate to them like they would any normal person.

A respondent said:

"When my brother was ill, we shared the same room until he died."

On how they will feel if a member of their family had HIV/AIDS, most caregivers talked about the pain of seeing them go through illness and death and felt sorry for the PLWHA, although they expressed the embarrassment associated with a family member with HIV/AIDS, they were more concerned about the suffering the PLWHA goes through before he/she dies.

All the caregivers said they would relate normally with PLWHA.

On isolation of people with AIDS all the caregivers were of the opinion that PLWHA should not be isolated, due to their closer ties with PLWHA, and the HBC health workers, they have come to accept PLWHA as any other sick person, who needs relatives around them to encourage them and show love to them.

A caregiver disclosed:

"They should not be isolated because the person might be strong, and productive, if the person is weak, the family should help because we know that caring will not infect you"

4.5.3 Family Members Without AIDS

Respondents in this group generally had a negative attitude about HIV/AIDS and PLWHA; this probably is because most of them have not encountered a PLWHA.

A few respondents said they had seen a person with AIDS, but their remarks about how a PLWHA looked like was negative.

A respondent said:

"I saw somebody with AIDS once, the person had lost a lot of weight and talked like a cat"

Most of the FWOPLWA felt that PLWHA deserved their fate, and that they are suffering as a consequence of their bad sexual behaviour, those who felt sorry PLWHA were quite judgmental, they were of the view that, apart from the suffering that PLWHA go through, they will also have to answer to God.

A respondent said:

"I will not be sorry for a PLWHA because they deserve their situation"

All respondents felt people with AIDS in the family have brought disgrace to the family, but they would relate normally with PLWHA.

When FWOPLWA were asked whether PLWHA should be isolated, there was collective response that PLWHA do not deserve to be among "healthy" people and should be sent as far away from the community as possible.

4.6 RESULT OF THE SEMI STRUCTURED QUESTIONNAIRE ON ATTITUDE TOWARDS HIV/AIDS AND PLWHA

Table 4.8 Feeling about PLWHA

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Feelings About PLWHA	No	%	No	%	No	%
Sympathy	20	91	20	100	19	82
They Deserve It	2	1	0	0	2	9
Apathy	0	0	0	0	2	9

Figure 4.7 Results of Semi Structured Questionnaire on feeling for PLWHA

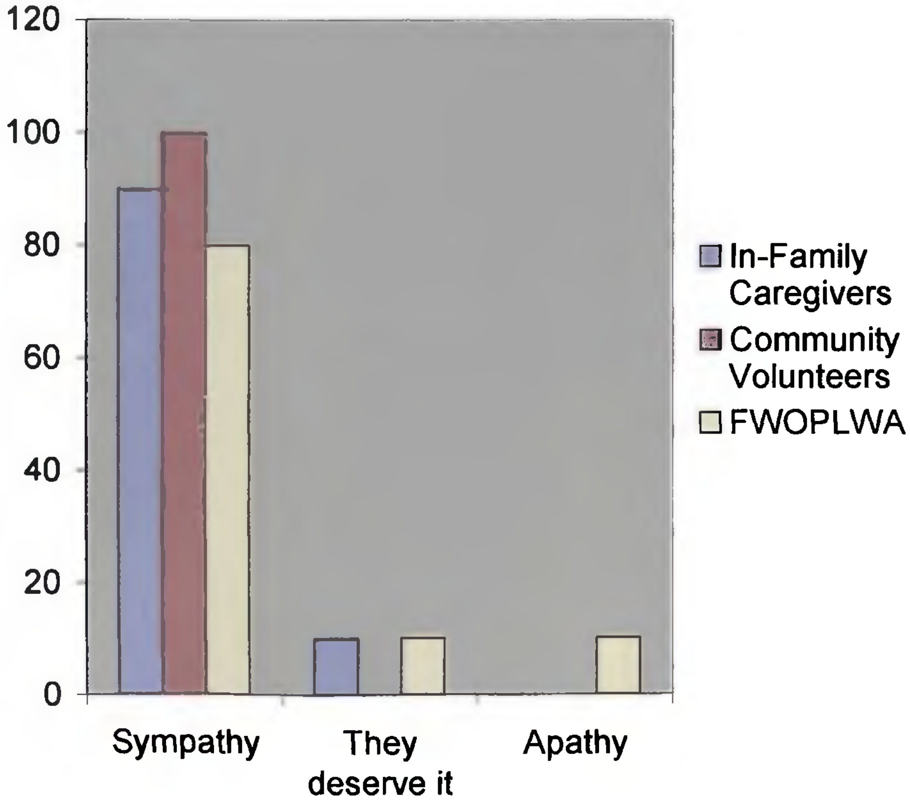


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Table 4.9 Isolation of PLWHA

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Isolation of PLWHA	No	%	No	%	No	%
YES	4	18	2	10	15	66
NO	18	82	18	90	8	34

Figure 4.8 Results of Semi Structured Questionnaire on isolation of PLWHA

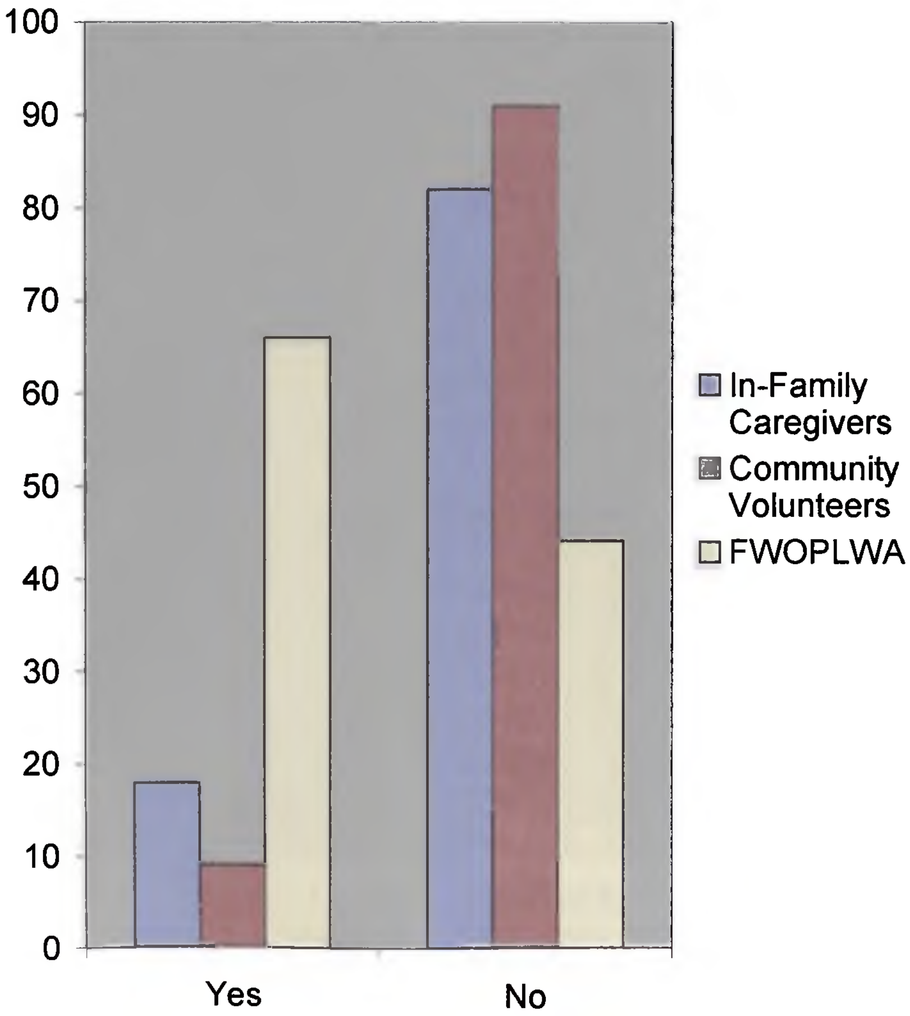
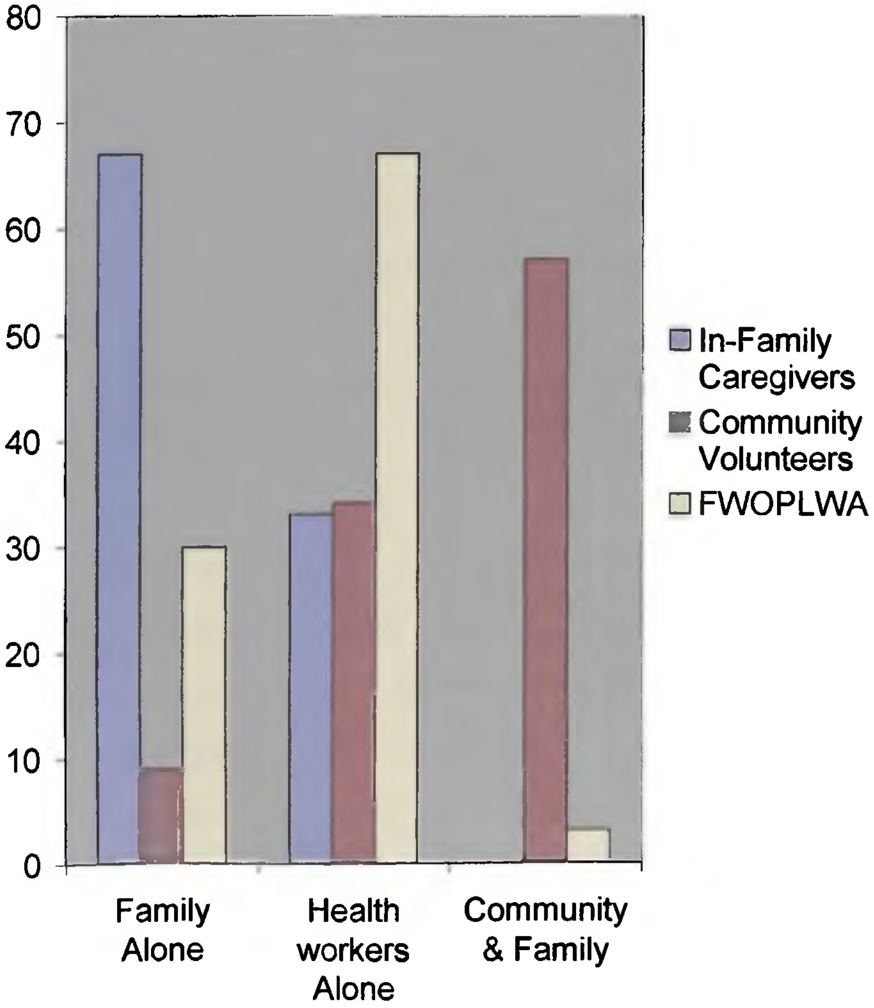


Table 4.10 **Caring For PLWHA**

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Care of PLWHA	No	%	No	%	No	%
Family Alone	15	68	2	10	7	30
Health Workers Alone	7	32	7	35	15	67
Community and Family	0	0	11	55	1	3

Figure 4.9 **Results of Semi Structured Questionnaire on Caring for PLWHA**



4.7 PRACTICES AND BEHAVIOUR

FOCUS GROUP DISCUSSION

4.7.1 Community Volunteers

Most of respondents considered a spouse or a regular girlfriend/boyfriend as a sexual partner, and most of them had only one *sexual* partner.

Generally all the volunteers said they had only one sexual partner who was a spouse or a girl/boyfriend, they felt that irrespective of the availability of condoms, one still had to stay with one sexual partner.

On the meaning of "safe sex", most volunteers understood it as staying faithful to your sexual partner, testing each other for HIV/AIDS before marriage and condom use.

Volunteers said their source was mainly from the drug stores and family planning clinics. Most volunteers responded that because condoms were not always available at these sources, they always had extra condoms; they also made sure they always checked the expiring dates on the condoms.

When asked if they knew somebody who had changed behaviour due to HIV/AIDS in the family, most volunteers knew somebody who had changed behaviour.

All volunteers affirmed that the HBC programme has brought a change in behaviour on their parts, their behaviour, change ranged from sexual abstinence, faithfulness, to condom use:

A young volunteer said: " The *HBC programme has helped me, I have changed my behaviour, now I have a condom beside my bed, anytime I stretch my hands I can touch one"*

An elderly volunteer responded that: "*Yes, I have changed my behaviour, my wife traveled three months ago, I swear I have not have not touched any woman since she left."*

4.7.2 Caregivers of PLWHA

Most caregivers responded that a sexual partner was your spouse, or girlfriend/boyfriend, on the number of sexual partners, one would have expected all caregivers (because of their experience of caring for PLWHA) to say they had one partner, but a few said they had more than one partner.

On the meaning of "safe sex" the responses ranged from staying faithful to your partner, use of condoms, to testing each other before marriage, those who responded that "safe sex" meant condom use were asked about the possibility of the condom tearing,

A respondent replied, "*If you wear it well, it will not tear*"

The source of condoms for most caregivers was the drug stores and family planning unit, they said although condoms might not be available always in drug stores, the hospitals always had condoms.

Most caregivers knew people who had changed their behaviour due to HIV/AIDS in family.

A respondent said:

"I know somebody who is not flirting around because of seeing a person die of AIDS."

The caregivers themselves responded that they had changed their sexual behaviour because of the education from the HBC programme, and the pain and suffering they saw their relatives go through due to AIDS.

4.7.3 Family Members Without AIDS

4.7.4

Family members without AIDS had quite different sexual practices from the volunteers and caregivers, most respondents felt that a sexual partner was anybody you slept with and that you could have as many sexual partners as you could.

When asked what "Safe Sex" was. A respondent said:

"Safe Sex is sex with somebody you trust".

The source of condoms was from drug stores, and the hospital, although they all agreed that condoms were not always available at these sources.

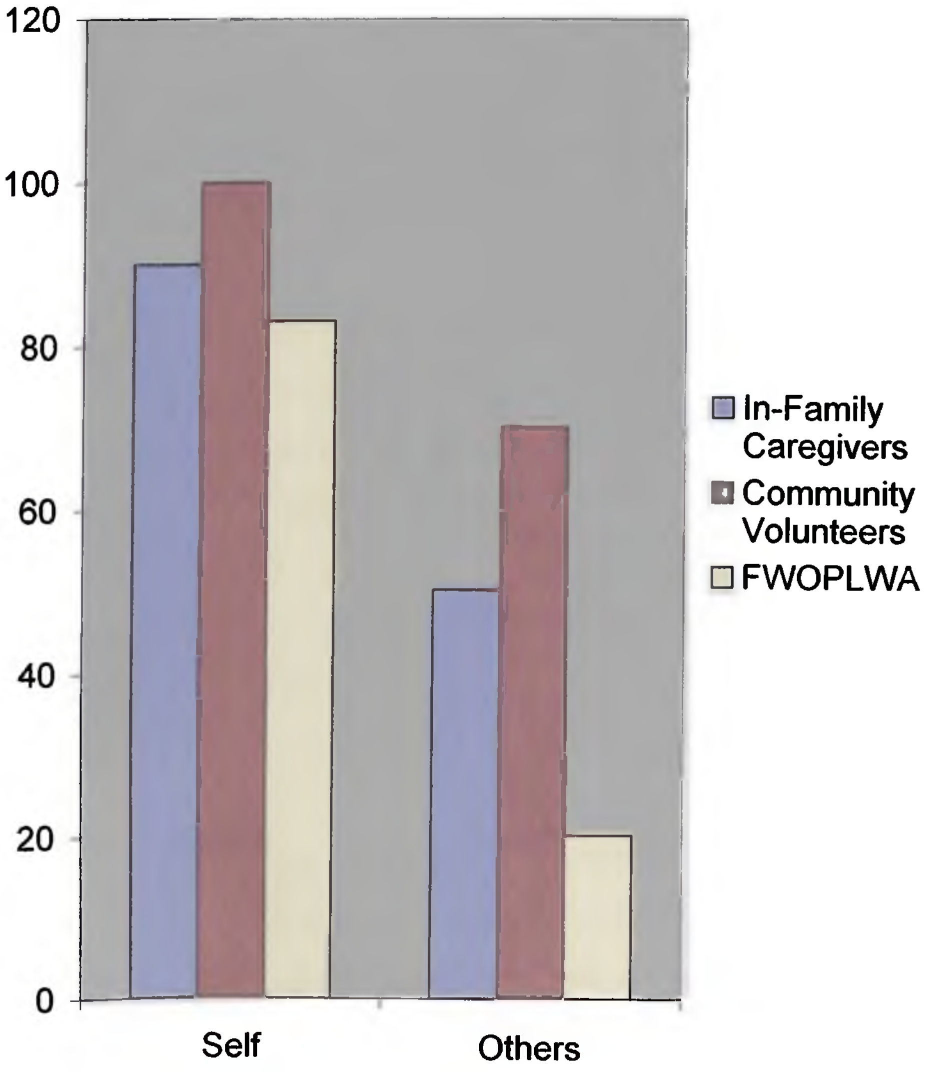
On behaviour change, most FWOPWA said the HBC programme has helped educate and brought about behaviour change in young people, but they did not know people who had changed their behaviour due to HIV/AIDS in the family.

Some respondents in the group said they have changed their behaviour. They do not engage in casual sex anymore, they use condoms, and don't share blades with anybody, although most of them would share blades with their spouses. Their change in behaviour is due to the health education talk they received by the HBC team.

Table 4.11 Behaviour change due to HIV/AIDS

	In-Family Care givers		Community Volunteers		FWOPLWA	
Total No Of Respondents(n)	22		20		23	
Behaviour Change	No	%	No	%	No	%
Self	20	90	20	100	19	83
Others	11	50	14	70	5	21

Figure 4.9 Results of Semi Structured Questionnaire on Change in Behaviour



4.8 VIEWS ON HBC PROGRAMME

4.8.1 Community Volunteers

When the question of who should care for PLWHA was put to volunteers, they all responded that after discharge from hospitals, the community should care for them; most of them gave decongestion of the hospitals as their reason for this view.

One volunteer said:

"If the person stays in the hospitals, government will spend a lot of money in caring for the person, and many beds will be occupied, those without AIDS will have no beds".

One volunteer simply said: *"Home care is the best"*

Volunteers were asked how the HBC programme has affected community interest in HIV/AIDS, all the volunteers agreed that because of the educative programmes of the HBC, the youth have been sensitized and awareness created in them about the dangers of risky behaviour, and the pain and suffering related to dying of AIDS.

One respondent said:

"In my community I have taught the youth about the dangers of HIV/AIDS, they have had behaviour change, also when the AIDS victims are laid in state after they die, and the youth see how ugly and bony they became before they died, they changed their behaviour immediately"

The volunteers also affirmed that the churches and durbars are well patronized when the community members realize that the topic to be discussed is on HIV/AIDS.

On the role of HBC in the fight against AIDS, most respondents said the HBC plays an educative role, it has helped sensitize people about HIV/AIDS, they also said HBC has relieved the health system of the burden of caring for PLWHA.

A respondent said:

"PLWHA do not frequent hospital anymore, because we give them all the care they need"

4.8.2 Caregivers

Most of the caregivers responded that family, specifically wife, children, and siblings, should care for PLWHA.

The caregivers all agreed that the HBC programme has sensitized community about HIV/AIDS. Caregivers see the HBC programme as a way of learning about HIV/AIDS and helping family with the care of their relatives.

4.8.3 Family members without AIDS

Respondents in this group generally felt they PLWHA should be cared for in the hospital, because they would receive better treatment at the hospital.

A respondent said:

"We have lepers, who stay in Leprosarium so if a person has AIDS and the family is poor, the government should keep the person until he dies"

The respondents in this group felt the main role the HBC programme was playing in the community was educative.

4.9 COMMUNITY PARTICIPATION IN THE HBC PROGRAMME

The analysis of community participation began by identifying, the major categories of information, which emerged, these were:

- Primary and secondary stake holders of the HBC programme;
- Community mobilization and sensitization;
- Community empowerment-capacity building;

- Planning and implementation of HBC programme;
- Monitoring and supervision of programme within the community;
- Ownership of the HBC programme;

4.9.1 Stakeholders

Through interviews with the PHC, HBC coordinators and the opinion leaders, the primary stakeholders identified in the HBC programme were the community members, the secondary stakeholders were the health workers and the donors, the main groups in the communities involved in the programme are the Churches, the Village health committees, Unit committees and the Traditional birth attendants (TBA).

4.9.2 Community mobilization and sensitization

The community was mobilized using the Rural Rapid appraisal method, this involved the participation of all stakeholders, (Community members and health workers) the different categories of health workers debated on health issues, methods used were diagnosis, ranking, mapping, direct observation and time trends, this allowed for even the illiterate subjects to participate, at the end of the programme, they came to the conclusion that HIV/AIDS was a community problem and that health workers alone should not be the only people involved in the care of PLWHA, the community needed to play a part in the care of PLWHA.

One opinion leader said: "W*e heard about AIDS, we didn't know how it looked like, after the health workers sat down and described the disease to us, how people fell sick and loose weight, we realized we did have such people amongst us, and we realized the need to help care for them, and educate peopled not to get infected*"

4.9.3 Selection of Volunteers

The PHC coordinator and his team approached the chiefs, opinion leaders, queen mothers, and churches to bring people who will form part of community volunteers for the HBC programme, different groups were targeted, and they selected volunteers.

4.9.4 Community Empowerment

After the selection the volunteers were invited to the Agogo hospitals for a training workshop, they were taught on female and male reproductive health, counselling of PLWHA, signs, and symptoms of HIV/AIDS, modes of transmission, prevention.

They were also given skills on how to give nursing care to PLWHA. Volunteers were taken through record keeping, how to administer certain medications and referral of serious cases to hospital.

4.9.5. Implementation of programme

The work of the community volunteers involves giving physical, emotional, and spiritual support to PLWHA; they also educate relatives of PLWHA and the public.

The community volunteers are immediately notified when a person is diagnosed as HIV positive, as a member of the group called “Friends of the sick” they then talk to the person to find out who else knows about their HIV status, if any other member of the family knows, that person is also brought on board, the PLWHA is visited by volunteers, those who need nursing care are nursed with the help of the family, those who are still strong are counselled and advised on diet and medication.

4.9.6 Monitoring and supervision

The work of the community is monitored and supervised by the HBC team health workers from the Agogo hospital; they visit them quarterly with a checklist for monitoring.

Most communities have a health committee that monitors and supervises the work of the volunteers.

After going round to visit the sick, all volunteers and OPL meet at the end of the day to review the day's work, all problems that arise are thrashed out.

4.9.7 Community Ownership of programme

All the eight communities were involved in the planning and implementation of the HBC programme from the beginning.

Community ownership of the project is indicated by their willingness to provide human, material, and financial resource for the programme, from the interview with the PHC and HBC coordinators there is willingness on the part of community to provide human resource, but the financial resource is lacking.

The communities have no income generating activities put in place to sustain the programme, when community opinion leaders were asked who they think should mobilize funds for the HBC programme most of the respondents replied that funding for the programme was the duty of the government, they also said they had not thought of any plans to generate funds for the programme.

4.10 PROBLEMS AND SUGGESTIONS

4.10.1 Community Volunteers

Volunteers gave their problems with the HBC programme as lack of financial and material support, and sometimes-hostile reactions from relatives of PLWHA.

All volunteers wanted government to give them some monthly allowance, to encourage them in their work, they also suggested they be given protective materials like gloves and bleach. Each volunteer wanted a first Aid box to carry during visits. They all agreed that they should be given bicycles so that they could assess the remote communities

4.10.2 Caregivers

The caregivers gave their problem with the HBC programme as lack of communication between them and the volunteers about the illness of their relatives, the caregivers said that though most of them their relatives have AIDS, the volunteers don't actually tell them this, they are only taught how to give care to the PLWHA, they only get to know the diagnosis after the PLWHA dies.

Caregivers were of the opinion that the work of the volunteers was hard and they should be given incentives to encourage them. They also suggested that the caregivers and volunteers be given first Aid boxes containing simple medications like ORS, Analgesics, and G-V paint to help their work become easier.

4.10.3 Opinion Leaders

The main problems the OPL had with the HBC programme were the lack of incentives for the volunteers, and financial help to sustain the programme.

Another problem the opinion leaders had was the fact that they felt there were PLWHA in their communities who have not been to hospital to be tested, and therefore cannot receive any help from them.

An OPL said: "*We must be given the powers to send anybody who looses a lot of weight to the hospital for an AIDS test, so that we can follow the person up in the community*".

Most of the OPL said the volunteers needed bicycles to access remote areas, first Aid kits to help them in their work, and I.D cards for free medical care.

4.10.4 HBC Health workers, PHC/HBC coordinators

The problems this group had with the HBC programme was the lack of co-operation between the counsellors and the coordinators.

Suggestions this group had for improvement of the HBC programme was the need to come up with some form of income generating skills for the volunteers to help then contribute financially to the programme, they suggested more refresher courses, for counselors and volunteers and visits to neighbouring countries to see how other HBC programmes are operating.

CASE STUDIES

4.11.1 FIRST CASE STUDY

Jane (not real name) a twenty –seven year old J.S.S. dropout is a farmer in a semi-urban community, she is a single parent with two children, a seven year old son who lives with her mother in another town, and a five month old baby who lives with her in a friend's house. Jane's parents have been divorced for the past ten years, she used to live with her father and three other siblings until she quarreled with her father's sisters and decided to move out.

Jane was diagnosed as HIV positive seven years ago during her first pregnancy, child, and HIV test was done routinely for all who were coming to deliver at the hospital she was attending, she was also being treated for Buruli ulcer during the time of her pregnancy. A nurse from the hospital visited her at home to give her the news about her HIV status, " In fact when I was given this news I did not eat for three days, I wanted to kill myself but because of my child I held myself together." Her first baby tested negative and the second baby is yet to be tested.

Jane was counseled by the nurse who visited her at home, she was also invited to the hospital to meet the HIV team, she was educated about HIV/AIDS and advised on her diet, condom use during sex was suggested to her, and the nurse explained to her that having another child will weaken her immune system further. Jane was also given spiritual and moral support and advised by the hospital Chaplain who is the HBC coordinator. She did not heed to the advise of the nurse and had sexual relation with several men after her counseling. "I did not have money for food, and my child's father left me because he heard about my HIV status, so I decided to look for a man to take care of me. "Jane did not explain her HIV status to the men she slept with neither did she use condoms. "I suggested we use condoms but they refused, I know they could get infected and infect other women, used to think a lot about this",

Nobody in Jane's family knows of her HIV status, she is visited regularly by her HIV counselor, and they usually talk outside her house, the counselling sessions with the counselor has really helped her accept her situation, "I do not feel stigmatized, the counseling I received from the HBC team has really helped me, if I had listened to them and not gone in for a man I would be stronger now, I did not commit suicide because of the counselling, the counselling has helped me not to think of my situation too much."

Before Jane was tested, she did not know much about HIV/AIDS "I did not know much about AIDS, that is why I wonder why I became infected, it really surprises me. With the education from the HBC team I know it is a germ that causes AIDS and that a mother can give it to the baby during birth, it can also be acquired through sharing of blades and needles." This knowledge of HIV/AIDS did not translate into behaviour change on Jane's part. "Because of hardships I could not change my life style and got pregnant again, I have decided to leave my boyfriend and start work."

Jane is one of the first PLWHA to join the HBC programme, because she was not particularly ill when the programme started, she was given money to start trading, she was also recruited into a training programme for PLWHA, to learn how to make " tie and dye", which she completed successfully.

Jane has gained a lot from the HBC programme, she is entitled to free medical care, she has been given money several times to start a trade, she has regular counseling sessions with her HBC counsellor, which has helped retain her self confidence. She needs a loan to start her "tie and dye" business, but unfortunately her health has began to fail, and the HBC programme will have to discuss telling a family member who will care for her and her child when she can no more care for herself.

4.11.2 SECOND CASE STUDY

Ahmed (not real name) is a fifty three year old divorced father to three children; he is a farmer by profession and lives in an urban community. He traveled to the Ivory Coast ten years ago to seek greener pastures, and returned to Ghana after two years.

Four years ago he fell ill and was admitted to the hospital, during his admission, he fell into a coma and blood was taken from him for HIV test. The result came back positive, his doctor was the person who told him that he had AIDS, he was counselled by a HBC counsellor before discharge from the hospital, "the counselling has really helped me, they taught me about my diet, my sexual life, I take care of myself, anytime I am sick I come to the hospital for free treatment".

Ahmed came into contact with the HBC programme through a friend who introduced him to the HBC coordinator because he could not pay his hospital bills, he was immediately registered with the HBC programme and a volunteer has been visiting him at home regularly. Before he was diagnosed with HIV/AIDS he used to experience abdominal pains, fever, cough with bloody sputum, after diagnosis and treatment he has been well until a year ago when he started to experience diarrhoea, and skin rashes, before Ahmed joined the HBC programme he could hardly pay his hospital bills, " I used to have a little money to pay my hospital bills, but the money got exhausted, and I could no more afford the hospital bills, now I get help from the HBC programme, I don't pay hospital bills anymore"

Only Ahmed's brother knows his HIV status, his wife left him immediately he told her that he was HIV positive. Through the visits of the HBC volunteers his brother has understood his illness and empathizes with him, he has also changed his sexual behaviour.

Ahmed has benefited a lot from the HBC programme, “at first I used to think of my financial problems, I don’t think about this anymore, through the advice of the HBC. I go to all social gatherings, if I had not met them I would have been deformed by now, they have brought back my confidence as a human being. My hospital card is with the chaplain, so if I am ill, I come straight to her, pick my card and I am seen immediately, I don’t have to queue for my card or pay hospital bills”.

Ahmed used to feel stigmatized because he has AIDS, but he has now accepted his condition, after a series of counselling sessions with the HBC team, he now knows he is not the only person with HIV/AIDS, and feels less stigmatized.

He did not know anything about HIV/AIDS before he was diagnosed with AIDS, but now he knows it is caused by a virus in the blood, and that it is transmitted through sex, sharing of blades and blood transfusion, this knowledge has translated into behaviour change on his part, “there is a big change in my life, I don’t have sex with women anymore, I don’t share blades and shavers, and I talk to my children not to engage in unprotected sex, I even talk to my nephews and nieces, some of them have changed their behaviour some have not”.

Ahmed feels the HBC programme is helping in the management of HIV/ AIDS through it’s educational programmes, free medical care for PLWHA and the counselling sessions which encourages PLWHA to have hope in life.

4.11.3 THIRD CASE STUDY

Ama (not real name) is a thirty five year old widow and mother of three children aged between fourteen and seventeen years; she lives in a semi-urban community, has completed primary school and is a trader by profession, her husband died two years ago of AIDS.

Ama found out she was HIV positive seven years ago, during a visit to the hospital for malaria. Her husband had been diagnosed with HIV a few years earlier, but she was not told this, she only heard rumours in town that her husband was suffering from AIDS, she never discussed her HIV status with husband, only her sister and uncle know that she is HIV positive.

The HBC team members visited Ama after she tested positive, and she was advised to join the programme, her HIV/AIDS counselor visits her regularly at home. Discussions with her counselor has increased her knowledge about HIV/AIDS, although she was advised about her diet and the need to have protective sex, she continued to have unprotected sex with her husband. "We both continued to live a normal married life pretending we did not know we were both HIV positive, I did not want to discuss my situation with him because when he tested positive he did not tell me and continued to sleep with me." A volunteer visits her regularly at home.

Before Ama tested positive she did not know anything about HIV/ AIDS but now she knows how it is acquired and that if you eat well and take good care of yourself you can live long. The counselling sessions have also made her feel less stigmatized.

Currently she has been having frequent bouts of diarrhoea and abdominal pains, she is also loosing a lot of weight and has skin rashes, she is aware free hospital care and drugs is given to all HIV positive patients, but she feels reluctant to go to the office of the HBC coordinator because she does not want to associate herself with the HBC programme .Ama feels people will suspect her of having AIDS if she is seen regularly with the members of the team, she will like to associate with them secretly.

4.11.4 FOURTH CASE STUDY

Doris (not real name) is a forty three year old mother of five children, she is separated from husband and lives with her boyfriend in a large city, she has completed Middle school and is a trader by profession.

Doris was diagnosed as HIV positive three months ago at a hospital in her home town, she was not surprised when she tested HIV positive because whilst in the city she had been frequently ill, also her husband had many girlfriends and that was one of the reasons why she separated from him.

After she tested HIV positive she was taken to the office of the HBC coordinator and counseled, the counselling has helped her cope with her condition, "if I tell you that I am sad I will be lying, the counselling has really helped me, I feel like a normal person, the HBC team members relate well to me and I don't feel stigmatized.

Doris has told her brother (an HBC community volunteer) about her condition but nobody else in her family knows she is HIV positive, she does not intend to go back to the city; she intends to stay in her hometown and do some farming with her sisters.

The HBC programme has given her free access to healthcare in terms of drugs and consultation, the programme has also increased her knowledge about HIV/AIDS, she has also changed her sexual behaviour, "because of the discussions I have been having with the HBC counsellors I know that I should not be sleeping around with men.

CHAPTER FIVE

DISCUSSIONS

The study sought to examine the knowledge, attitudes, behaviour and practices on HIV/AIDS between in-family caregivers of people living with HIV/AIDS, community volunteers and family members without AIDS to see if there were differences between these groups, and whether the HBC programme could be used as an effective IE & C tool on HIV/AIDS, it to examined community participation in the HBC programme and the effect of HBC programme on PLWHA.

The study identifies the problems that the HBC programme in the Agogo sub district encounters and makes recommendation on how to improve on the programme.

The discussion will be undertaken according to the various sub-headings that emerged from the data.

Knowledge And Attitudes

The data presented under findings show that there were varying degrees of knowledge among the respondents. The knowledge about HIV/AIDS amongst the community volunteers and in-family caregivers was quite high, whilst the knowledge of FWOPWLA was average.

(Refer Figures 4.2, 4.3, 4.4, and 4.4)

The basic facts looked into were, cause of HIV/AIDS, modes of transmission of HIV/AIDS, signs and symptoms of AIDS, who is at risk of getting HIV/AIDS and measures of control and prevention of HIV/AIDS.

The factors, which most influenced knowledge about HIV/AIDS, were involvement with the HBC programme and source of information about HIV/AIDS.

William et al (1995) observed that home care helps to spread knowledge and awareness of HIV and AIDS within the community, and can serve as an entry point for HIV/AIDS education and prevention at the family and community levels.

All respondents agreed that HIV/AIDS is transmitted through sexual intercourse, however most of them were uncertain about other modes of transmission, less than half of respondents knew about transmission from mother to child, contaminated instruments and blood transfusion, (figure 4.3), such detailed knowledge is important in enabling people to judge attitudes towards PLWHA and their degree of personal risk, in a survey of knowledge, attitudes, and risk estimates concerning HIV/AIDS in Zimbabwe, it was observed that lack of detailed information usually made available by mass media campaigns are the result of gaps in the knowledge base of students (Anyadi, 1994).

In-family caregivers seem to attach risk of HIV/AIDS with prostitution, (figure 4.4). This response also reflected in the FGD, a caregiver said, "Women who flirt around and prostitutes are at risk of getting AIDS, they can also infect their husbands" This response can be explained by the fact that most of their relatives return from foreign countries ill, and eventually die of AIDS, hence it is assumed that whilst in the foreign countries they were involved in commercial sex work; In-family caregivers therefore label HIV/AIDS with prostitution.

The HBC community volunteers and in-family caregivers who had experienced caring for PLWHA, through the HBC programme, had a positive attitude towards PLWHA; this group had a better understanding of HIV/AIDS, which translated into a positive attitude.

Majority of in-family caregivers and community volunteers felt sympathy for PLWHA (figure 4.7) whilst FWOPWLA felt that PLWHA deserved their fate, this response is reflected in the FGD.

Community volunteers and in-family caregivers did not favour isolation of PLWHA but FWOPLWA felt that all PLWHA must be isolated. Sixty-six percent of FWOPLWA agreed to isolation. This is reflected in the FGD when one FWOPLWA member said: "Government should not let HIV positive people loose on the streets".

Respondents from all the three groups would be embarrassed if a family member were diagnosed with HIV/AIDS, and all felt that death from AIDS was associated with shame and disgrace to the family. The study showed that involvement in a HBC programme and care for PLWHA had not made any difference in the stigma that people attach to HIV/AIDS.
Experience with PLWHA brought about better understanding and positive attitude, which did not favour isolation of PLWHA but this experience, did not help reduce the stigma attached to the disease.

Family members without AIDS had a negative attitude towards PLWHA, this group is not only embarrassed when a family member has AIDS but actually favour isolation, although knowledge about AIDS is important, attitudes towards PLWHA must be favourable, as this will enhance any change in behaviour, it is known that knowledge about AIDS is generally unrelated to behaviour without modification of attitudes and belief.

Behaviour

A study in 1996 observed that for prevention programmes to result in sustained behaviour change, a sense of self-efficacy, defined as the conviction that one can successfully execute the behaviour required to produce the desired outcome, must be instilled in the target population.

Becker1974 also explains that an individual will not take any preventive measures unless he/she views himself/herself to be highly vulnerable to the disease, behaviour would not proceed until the attitudes that underline the motivation to perform or not to perform health related behaviour change. It is also argued that HIV is a highly stigmatized condition and attitudes will play a larger part in altering behaviour. In this study, community volunteers and in-family caregivers mentioned changes in their behaviour as well as other family members, whilst fewer FWOPWLA had changed behaviour, or knew people who had changed behaviour (Figure 4.10).

In-family caregivers and community volunteers through direct experience with, or observation of the HBC programme's activities have come to believe that HIV/AIDS is real and to accept PLWHA, this has led to a positive attitude towards PLWHA and behaviour change.

Results from the study show that AIDS is still a stigmatized disease, because of the stigma, people are less likely to adopt preventive strategies, seek treatment for opportunistic infections and STI's, seek counselling, access good quality care, disclose their status, and comply with treatment. Stigma compounds the tendency to see PLWHA, and not HIV as the threat, ignoring individual behaviours that put them at risk.

This study shows that the HBC programme can help people accept PLWHA, therefore adopting preventive measures knowing that the problem is with identified behaviour than with PLWHA.

Source of information about HIV/AIDS

The respondents gave their main sources of information about HIV/AIDS as Radio, Church, and health workers, friends, posters, T.V., and newspapers (Figure 4.1).

All the respondents gave the Church as a creditable source of information; therefore, the church can be used as a successful tool for communication. Anyadi (1994) recommended that health educators should target the churches when planning activities, this is because the church is a trusted source of communication and has networks that penetrate the remotest rural areas where government structures might not be available.

Some religious beliefs can bring about negative attitudes towards some of the preventive measures and PLWHA. Some churches view HIV/AIDS as Gods punishment to people who are sexually promiscuous.

It is clear that although the church does not preach fear, the underlying message is that immoral sinful behaviour leads to death from HIV/AIDS. Many religious bodies also see the suggestion of the use of condoms use as an encouragement of sex outside marriage.

Most respondents in all groups also mentioned the mass media as their source of information, Hubley (1988) mentions that mass media is the best method for rapid spread of simple information to a large population at low cost, the fact that the media does not give opportunity to people to ask questions to clarify some misconceptions is very important in planning programmes for HIV/AIDS.

Face-to- face methods are slower for spreading information in a population, because of the need to mobilize fieldworkers, and travel to different communities to hold meetings; however the opportunity to ask audience questions and obtain feedback gives face-to-face methods a powerful advantage. Most in-family caregivers and community volunteers also mention talks by HBC health workers as a credible source of information on HIV/AIDS.

Mass media messages are directed to an individual, HIV prevention efforts should not focus on individuals only. Rogers argues that more effective communication occurs when two individuals share common meaning, and mutual sub-cultural language and are alike in personal and social characteristics; their communication of ideas is likely to have greater efforts in forms of knowledge gain, attitude change and formation as well as convert behaviour change

(Rogers 1993).

Because in the Agogo community the HBC health workers come from the same community or have lived there a long time, they share common culture with the community members. Communication is therefore rewarding for both in-family caregivers and volunteers and HBC health workers; the knowledge of the in-family caregivers is increased due to the repeated visits and interaction with HBC health workers and community volunteers.

From the above discussions it is obvious that if family members are made to care for PLWHA not only will the burden on the overstretched health system be alleviated, but will increase the knowledge of caregivers and volunteers about HIV/AIDS, it will also create a positive attitude towards_PLWHA which will be a step towards a supporting environment, this will result in a sustained behaviour change and eliminate stigmatization.

Community Participation

Community mobilization, which aims to promote the involvement and participation of patients, family and community in HBC is a key strategy in developing a successful HBC programme, in order for the HBC programmes to be sustainable, communities must identify their own needs and participate fully in the process from the start, by involving the community members in taking care of PLWHA's the community is sensitized on the importance of HIV/AIDS. Communities and individuals can play the role of health promoters and educators if they have been empowered. The HBC programme is supposed to have a twice-yearly refresher course for community volunteers, but this study observed that these courses are organized as and when funds are available. Training, maintaining and supporting volunteers is an issue that demands attention if the HBC programme is to be sustainable.

The HBC health workers effectively do monitoring and supervision, self-monitoring takes place within the communities.

Provision of human, material, and financial resource indicates community ownership of the programme. In the HBC programme at Agogo, all the eight communities put in human resource, and a limited amount of material resource, the opinion leaders however feel government should provide the funding for the programme .Because all health programmes in the sub-district is funded by the government and the Presbyterian mission the opinion leaders do not see the need to mobilize funds within the community to sustain the HBC programme. The eight communities involved in the HBC programme do not have any income generating activities to support the programme, and opinion leaders have not thought of any income generating activities to sustain the HBC programme.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

The main conclusions of this study are that:

- A Home-Based care programme for HIV/AIDS has shown to be an effective way of changing attitudes about HIV/AIDS.
- High knowledge and positive attitudes about PLWHA has impacted on the behaviour of people involved in the HBC programme.
- An informal and more personal source of information about HIV/AIDS is an effective way of sensitizing people on HIV/AIDS.
- Counselling and education received by PLWHA through the HBC programme has led to the reduction of their feeling of stigmatization.
- Participation of community members is an essential and effective way of sustaining the HBC programme.
- Lack of cooperation between stakeholders of the HBC programme can affect sensitization of PLWHA about the existence of a home-based care, and the advantages of accessing the programme.

6.2 RECOMMENDATIONS

On the basis of these findings the following recommendations are being made for policy, research, and service:

- The Ministry of Health should integrate HBC into existing activities for HIV/AIDS in order to help overcome operational, technical, and social barriers to care.
- The overall profile of HBC needs to be increased by government to attract potential funding and strategic planners.
- All key stakeholders in the HBC should be made aware of the main goals and strategies of HBC so that each group has a better understanding about its role in the HBC programme.
- Hospitals in the district, which have HBC programmes, should supply all volunteers with medical kits stocked with relevant drugs and protective clothing to ensure best medical care of patients and prevent infection of caregivers as well as volunteers. Funding for this could be sourced from fundraising events organized by the district assemblies.
- Parliamentarians should be encouraged to engage in policy dialogue to ensure that the HBC programme ranks high on the National Agenda.
- Cash incentives should be given to HBC community volunteers by the traditional authorities to boost their morale.
- Community volunteers and Health workers must have regular refresher courses and have opportunities to visit other countries or regions where HBC programmes have been in existence for a long time, to learn from their experience. Sponsorship for this could be sourced from NGOs and other stakeholders.

- The District Assemblies, Ministry of Health/Mission Health Association of Ghana, and Community based Organizations should collaborate, cooperate and coordinate their efforts in setting up HBC programmes for people living with AIDS, through forums, and workshops at both district and national levels.
- The HBC programmes should have funds set aside for people living with AIDS and their orphans, so that they would not be reduced to destitution.
- Key stakeholders must carefully and systematically implement empowerment of the communities.
- Donors and Government strategists must promote community participation and ownership.
- Community support groups in which all stakeholders of the community are represented should be recognized by government as a cost effective strategy to represent the HBC programme.

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APPENDIX A

Semi-Structured Questionnaires

Section A

Age: _____

Sex: ______

Religion: __________

Ethnicity: ___________

Marital Status: ___________

Number of Children: __________

Educational Background: _______________

Section B

KNOWLWDGE ABOUT HIV/AIDS

1. Have you about the disease called AIDS? Yes____ No_____

   If yes, go to Question 2.

2. Where did you hear about AIDS?

   a. ____

   b. ____

   c. ____

   d. ____

   e. ____

3. What causes AIDS?

   a.
   b.
   c.

4. How is AIDS transmitted?

___

___

___

5. Who is at risk of getting HIV infection?

___

___

6. Do you think a person with the AIDs virus can look healthy?

   Yes _____ No _____ Don't Know _______

7. a. Can the germ be passed on to somebody else?

   Yes _____ No _____ Don't Know _______

   b. If yes, how is it passed on?___

___

c. How long is the incubation period for HIV infection.

___

8. Does AIDS have a cure?

Yes _____ No _____ Don't Know _______

9. What are some of the signs and symptoms of HIV/AIDs infection?

____

____

____

10. How can HIV/AIDs infection be prevented?____

____

____

____

11. a. Is there a link between HIV/AIDs and STDs?

Yes _____ No _____ Don't Know _______

b. If yes, what is the link?

____

____

ATTITUDES

12. How do you feel about PLWA? (People living with AIDs)

____

____

____

13. How will you relate to a PLWA?

____

____

____

14. Would you be embarrassed if a member of your family is diagnosed with HIV/AIDs?

Yes _____ No _____ Don't Know ________

b. Why?

____

____

____

15. Do you think people with AIDs should be isolated?
Yes ______ No ______ Don't Know ________

16. What do you think about death?

____

____

17.What do you think about death from HIV/AIDs?

____

____

____

18.What effect does HIV/AIDs have on families?

____

____

____

PRACTICES

19. Do you practice sex?
Yes_________ No________

19b. If yes what types of sex do you practice? ___________________

20.How many sexual partners do you have? _________________

21.What is safe sex?

____

____

____

22.How often do you have sex? ____________________

23. Do you use condoms during sex?
Yes______ No________

b. If yes where do you get your supply of condoms?

____

____

____

c. Is your source of condoms always available? Yes______ No______

24.Do you share blades or shavers with anyone?
Yes_______ No______

24b.Why?

____

____

25. Have you ever engaged in prostitution?

Yes_______ No_______

26.Do you know anybody who has changed his/her behaviors as results of AIDs in the family?

Yes _____ No _____ Don't Know _______

26b, If yes, in what ways has the person changed his/her behavior?

____

____

____

____

27. What do you think brought about this behavior change?

____

____

____

____

28. Have you made any changes in your life as a result of the HBC program of HIV/AIDs disease?

Yes ______ No______

b. If yes, what are these changes?

____

____

____

29. Who do you think should care for people living with AIDs?

____

____

29b.Why?

____

____

____

30. What is your view about home-based care for people living with AIDs?

____

____

____

PROBLEMS AND SUGGESTIONS

31. Do you think the HBC program has a role in the fight against AIDs?

Yes _____ No _____ Don't Know _______

b. If yes, please explain this role:

____
____
____
____

32. Do you have any problems with the HBC for people living with AIDs?

Yes _____ No _____ Don't Know _______

b. If yes, what are they?

____
____
____
____

33. What are some suggestions you would make in solving those problems?

____
____
____
____

34. What further comments, suggestions or criticism would you like to make about HBC programs.

____
____

In – Depth Interview Guide

Target; People Living With Aids (PLWHA).

Section A
Greetings
Introduction
Explanation of purpose of interview.
Permission to record session.

Section B
Age;
Sex;
Occupation;
Marital Status;
Education;
Number Of Children;

Section C
What do you think is the most important health issue in Ghana today? Why?
What about your community?

1. When did you find out you were HIV positive?
   Where were you told?
   Who told you?
   How were you told?

2. How did you feel when you were told you were HIV positive?
   Probe- The thoughts that went through mind.
   Describe exact feeling at the time.
   The immediate reaction..

3. Did you have a pre and post test counselling?
   Has the counselling affected the way you are dealing with your HIV status?
   If yes, in what way?

4. What common ailments have you been experiencing before and after you were diagnosed with HIV/Aids?

5. Were you having difficulties in paying your medical bills? In what way?

6. How did you come into contact with HBC team?

7. Has the HBC programme benefited you and your family?

IN DEPTH INTERVIEW GUIDE

TARGET: OPINION LEADERS, HBC/PHC COORDINATORS

Section A

Greetings
Introduction
Explanation of purpose of interview.
Permission to record session

Section B

1. What is the most important health concern in Ghana today?
   –What about your community?

2.Could you please give a brief account of how the HBC programme was introduced to your community.

Probe- When the HBC programme was introduced.
How the was community approached with this programme.
How did the community come to the conclusion that they had a problem which needed a HBC programme.

3. Please describe the part the community played in the setting up of the HBC programme.

4.. How were community volunteers recruited into the programme?
Probe-Were existing volunteer groups used in the recruitment of volunteers for HBC programme?
Describe the work of the volunteers.
How long do volunteers stay in programme?
What are the reasons why some volunteers leave the programme?
What incentives are given to volunteers to encourage them to stay in programme.

5.What measures has the community put into place to monitor the work of the HBC Community volunteers?

6.How will the community be able to sustain this programme after the donors withdraw their support?

7.Has the community identified other stakeholders for the HBC programme?

Problems and suggestions

8.Do you think this programme is acceptable to the community?
Explain why.
What problems do you anticipate with the programme?
9.Could you describe the difference the HBC programme has made in the lives of PLWA/general community.
In terms of – Behaviour Change
- Standard of living
- Stigmatization of PLWA and their families
10.What do you see as the shortcomings of the programme?
- How would you like the programme improved.