

HIV and AIDS: An analysis of community coping strategies with special reference to Mutambi Ward community of Zvishavane, Zimbabwe

By

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ASO	AIDS Service Organisation
BEAM	Basic Education Assistance Module
CBO	Community Based Organisations
DAAC	District AIDS Administrative Committees
FAO	Food and Agricultural Organisation
FGD	Focus Group Discussion
GMB	Grain Marketing Board
GTZ	German Technical Cooperation
HBCP	Home Based Care Programme
HEPS	High Energy Protein Supplement
HIV	Human Immunodeficiency Virus
IDRC	International Development and Research Centre
IDS	Institute of Development Studies
IEC	Information, Education and Communication
LDS	Lutheran Development Services
MDG	Millennium Development Goals
NACU	National AIDS Coordinating Unit
NAP	National AIDS Policy
NGO	Non-governmental Organisation
PLHIV	People Living With HIV and AIDS
ROSCA	Rotating Savings and Credit Association
SAFAIDS	Southern Africa HIV and AIDS Dissemination Service
SIMA	Systemwide Initiative on Malaria and Agriculture
STI	Sexually Transmitted Infection
TASO	The AIDS Support Organisation
TB	Tuberculosis
ULKRS	University Lake Kariba Research Station
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNDP	United National Development Programme

UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
UZ	University of Zimbabwe
VCT	Voluntary Counselling and Testing
WAAC	Ward AIDS Administrative Committees
WHO	World Health Organisation
ZFU	Zimbabwe Farmers Union
ZWRCN	Zimbabwe Women's Resource Centre and Network

ABSTRACT

The impact of HIV and AIDS on Mutambi Ward in Zvishavane District of Zimbabwe was assessed between May 2004 and October 2006. The study was undertaken using focus group discussions, questionnaire surveys, use of key informants, review of records and observations. Care for PLHIV has increased household labour requirements resulting in a decrease in the time allocated to crop production activities. Approximately 75% of the households spent their productive time caring for the sick and attending funerals which occur approximately 8 times a month. Resources meant for crop production are diverted to patient care. Only 33% of the members managed to work once a week on their plots while the rest were involved in HIV and AIDS related activities. This has negatively affected crop productivity. In order to cope with the excess burden of crop production and attending to PLHIV, the community has adopted various coping strategies, the main one being a community home based care programme run by 21 volunteers who dedicated their labour to help households affected by HIV and AIDS at the expense of their own productive work. Other coping strategies include change of cultural norms and values, change of roles and responsibilities, dependency on relatives and funeral contributions. The extent to which these coping strategies were effective was minimal. Thus coping with the impacts of HIV and AIDS by the community is a battle being lost.

Key words: HIV and AIDS, coping strategies, care and impact.

CHAPTER 1

1.0 Introduction

1.1 General Overview

One of the most formidable challenges the world faces today is HIV and AIDS. HIV and AIDS stand as the most complex development, health and social challenge the world is facing. AIDS is by far the biggest killer in Africa and other developing countries, claiming millions of lives annually, and accounting for high levels of morbidity to millions more (Review of African Political Economy, Special Issue on AIDS, 2003:3). The HIV and AIDS burden has continued to increase globally and more so in Africa. The Joint United Nations Programme on HIV and AIDS (UNAIDS) Report (2007:1) still reflects the disproportionate distribution of HIV and AIDS in the world. The severity of HIV and AIDS varies considerably from one geographical area to another, but the general vulnerability pattern that emerges is related to other factors of a socio-cultural, economic, environmental, political and technological nature. With regards HIV and AIDS, for example, the hardest hit are those communities that are generally unempowered, that exhibit high levels of mobility, that have adopted socio-cultural practices that fuel transmission, and that are so poor that they lack access to basic social services such as health, education and adequate nutrition (Jackson 2002:48).

1.2 Global HIV and AIDS estimates

Table 1 below shows the latest statistics on the world epidemic of HIV and AIDS. These were published by UNAIDS/WHO in July 2008, and refer to the end of 2007.

Category	Estimate
People living with HIV/AIDS in 2007	33.0 million
Adults living with HIV/AIDS in 2007	30.8 million
Women living with HIV/AIDS in 2007	15.5 million
Children living with HIV/AIDS in 2007	2 million
People newly infected with HIV in 2007	2.7 million
Children newly infected with HIV in 2007	0.37 million
AIDS deaths in 2007	2 million
Child AIDS deaths in 2007	0.27 million

HIV and AIDS information from <http://www.avert.com> (20.10.09)

Global trends of HIV

Below is figure 1 illustrating the global trends of HIV from 1990 to 2007

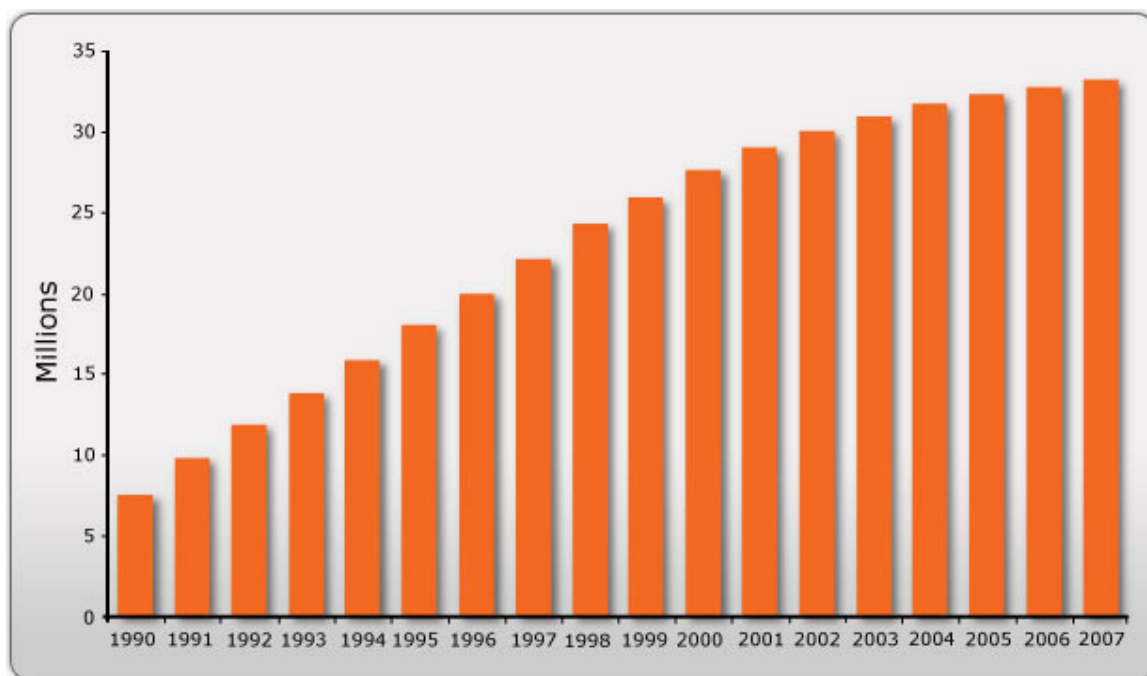


Figure 1 above shows the global trends of HIV from 1990 to 2007. Since 1990, the number of PLHIV has risen from 8million to 33million in 2007. A sharp increase is noted from 1993 to 2000. Since then the rise seems to be stabilising. Unfortunately, the majority of PLHIV are in Africa. Even though HIV prevalence rates seem to be subsiding in some African countries, more new cases are recorded in other countries contributing to a rise in the number of PLHIV in the world.

1.3 Regional statistics of HIV and AIDS

Table 2 below summarises the number of PLHIV per region

Region	Adults & children living with HIV/AIDS	Adults & children newly infected	Adult prevalence*	Deaths of adults & children
Southern Africa	22.0 million	1.9 million	5.0%	1.5 million
North Africa & Middle East	380,000	40,000	0.3%	27,000
Asia	5 million	380,000	0.3%	380,000

Oceania	74,000	13,000	0.4%	1,000
Latin America	1.7 million	140,000	0.5%	63,000
Caribbean	230,000	20,000	1.1%	14,000
Eastern Europe & Central Asia	1.5 million	110,000	0.8%	58,000
North America, Western & Central Europe	2.0 million	81,000	0.4%	31,000
Global Total	33.0 million	2.7 million	0.8%	2.0 million

<http://www.avert.com> (20.10.09)

- Proportion of adults aged 15-49 who were living with HIV and AIDS.

1.4 HIV and AIDS in Africa

Africa has been the continent worst affected by HIV and AIDS (UNADS 2007) and has so far recorded the highest number of orphans worldwide. Of the 11 million children orphaned by AIDS, 75% are in Africa <http://www.avert.com> (20.10.09).

In Somalia and Senegal the HIV prevalence is under 1% of the adult population, whereas in Namibia, South Africa, Zambia and Zimbabwe around 15-20% of adults are infected with HIV. In three southern African countries, the national adult HIV prevalence rate now exceeds 20%. These countries are Botswana (23.9%), Lesotho (23.2%) and Swaziland (26.1%) <http://www.avert.org/hiv-aids-africa.htm> 27.10.09.

There is evidence that the epidemic is slowing or stabilizing in Eastern and Western African countries. In Cameroon HIV prevalence is now estimated at 5.1% and in Gabon it stands at 5.9%. In Nigeria, HIV prevalence is low (3.1%) compared to the rest of Africa. However, because of its large population (it is the most populous country in sub-Saharan Africa), this equates to around 2.6 million people living with HIV. Adult HIV prevalence in East Africa exceeds 5% in Uganda, Kenya and Tanzania <http://www.avert.org/hiv-aids-africa.htm> 27.10.09.

More than 55 percent of the people infected with HIV or suffering from AIDS in Africa are women. For physiological and social reasons, women and girls are particularly susceptible to the sexual transmission of HIV and AIDS. Often bound by cultural traditions where women hold lower social standings than men, women cannot control their husbands' sexual behaviour, and have no voice in contraceptive choices. Other groups most vulnerable to the pandemic include, youth, older people,

transgender, people living in poverty, prisoners, migrant labourers, orphans, people in conflict and post-conflict situations, indigenous peoples, refugees and internally displaced persons, as well as HIV and AIDS outreach workers Randiver Vena Dr 2006:1.

1.4 HIV and AIDS in Southern Africa

Southern Africa has been hardest hit by HIV and AIDS and is home to almost two-thirds (62.5%) of people living with HIV and AIDS. This translates to 22 million people amounting to 11% of the world's population (UNAIDS 2007). The region is also home to most (91%) of the 2.3 million children living with HIV or AIDS globally. Almost all nations in this region have generalized HIV and AIDS epidemics and their national HIV prevalence rate is greater than 5%. In several, more than 10% of adults are already estimated to be HIV positive. South Africa has an estimated 5.5 million people living with HIV and AIDS, one of the highest in the world, and almost one in five South African adults are HIV positive. Swaziland has the highest prevalence rate in the world (33%), 23% in Lesotho, and 15.6% in Zimbabwe (UNAIDS 2007 http://www.kff.org/hivaids/upload/3030_9.pdf 16.10.09). Southern Africa remains the most heavily affected region within sub-Saharan Africa. In a number of countries in the region, the spread of the virus into the general population has exceeded what was previously considered possible. HIV and AIDS is the most fundamental underlying cause for what has come to be known as “the Southern African crisis”. Combined with food shortages and chronic poverty, HIV and AIDS become more deadly (S Lewis: 2006:6).

Despite these grim statistics, HIV prevalence in Southern Africa appears to be levelling off. It is thought that this stabilisation is due to behaviour change and increased HIV related mortality, which is the numbers of people becoming infected with HIV, is beginning to roughly match the numbers dying of AIDS related illnesses. HIV infection is becoming endemic in Southern Africa. Current high prevalence levels mean that even those countries that do eventually reverse the epidemic's course will have to contend with the serious impacts of the AIDS epidemic for many years. The havoc brought by AIDS will shape the lives of several generations of Africans (Mason, 2005: 6).

Adult HIV prevalence has been stable in recent years. But stabilisation does not necessarily mean the epidemic is slowing. On the contrary, it can disguise the worst phases of an epidemic where roughly equally large numbers of people are being newly infected with HIV and are dying of AIDS (UNAIDS HIV and AIDS epidemic report, 2004:28).

Across the region, women are disproportionately affected by HIV. Women represent almost half (48%) of all adults living with HIV or AIDS, and the number of women living with the disease has increased globally. In Southern Africa, women represent more than half (59%) of all adults living with HIV or AIDS (UNAIDS June 2007). Gender inequalities in social and economic status and in access to prevention and care services increase women's vulnerability to HIV. Sexual violence may also increase women's risk, as they are biologically more susceptible to HIV infection than men. The epidemic has multiple effects on women including added responsibilities of caring for sick family members; loss of property if they become widowed and/or infected; and even, violence when their HIV status is discovered (http://www.kff.org/hivaids/upload/3030_9.pdf 16.10.09).

Most countries in Southern Africa are experiencing generalized epidemics. HIV is spreading throughout the general population, rather than being confined to populations at higher risk, such as commercial sex workers and their clients, men who have sex with men, and intravenous drug users. In Southern Africa, heterosexual transmission is by far the predominant mode of HIV transmission 92%, 7% through Mother to Child Transmission of HIV (MTCT) and 1% by blood transfusion (Human Development Report 2003). At the beginning of the epidemic in this region, HIV infected men vastly outnumbered HIV infected women; today the situation in most countries is reversed (examples including South Africa and Zimbabwe). African women are being infected at an earlier age than men, and the gap in HIV prevalence between men and women continues to grow (<http://www.avert.org> 10.04.06).

1.5 HIV and AIDS in Zimbabwe

Table 3: PLHIV in Zimbabwe

HIV and AIDS in Zimbabwe

Population in 2008	12,500,000
People Living with HIV/AIDS	1,300,000
Women aged 15+living with HIV/AIDS	680,000
Children with HIV/AIDS	120,000
Adult HIV prevalence (%) 2007	15.6
AIDS Deaths in 2007	140,000

Source: <http://hivinsite.ucsf.edu/global?page=cr09-zi-00> 14.10.09

The HIV and AIDS prevalence rate in Zimbabwe has been levelling off significantly from over around 33.7% in 2002 to 18% in 2006 and then it fell again to 15.6% in 2007 (Ministry of Health and Child welfare (MOHCW) 2008. However, Zimbabwe still remains one of the countries where HIV and AIDS infection rates among the adult population exceeds 10 percent as is the cases with all countries in Southern Africa. Zimbabwe has one of the worst AIDS epidemics in the world and it has so far left behind an estimated 1.2 million AIDS orphans, UNAIDS 2007. AIDS had become the number one killer in the under five age group (Ministry of Health and Child Welfare, 2003:3).

By year 2000, HIV and AIDS had significantly reduced household production output to about fifty percent due to poor crop management (Zimbabwe Farmers Union, 2000:94). In addition, HIV and AIDS is having significant adverse effects on household composition, labour and income, leading to knock on effects on the household's food production, cropping patterns and livestock production activities, (Rugalema, 2004:576). The weakening of the public health sector since most PLHIV cannot access private health services due to the prohibitive medical fees has worsened the impacts. Most households have therefore assumed patient care activities (Baylies 2003: 486).

1.6 HIV and AIDS in Zvishavane

Zvishavane is one of the Districts worst affected by HIV and AIDS in Zimbabwe Ministry of Health and Child Welfare 2003. This is because it is a mining district with asbestos, emeralds and other precious stones being key minerals. As a result, a large

proportion of its population is of a migrant nature because adults usually males migrate from one mining settlement to another and are constantly on the move in pursuit of informal mining ventures frequently leaving their spouses and children at home. Cross border trade was also another activity that made the community to become highly mobile. Cross border trade in countries including Botswana, South Africa, and Mozambique was ranked number 3 by the community as an income viable income generating activity and 45% of respondents mentioned that cross borders were on the increase in the community. Though the HIV prevalence rate for the District could not be established, the situation of high mobility made this community vulnerable to HIV infection. According to the Ministry of Health and Child Welfare 2003, 75% of all hospital admissions and 59% of all deaths at Zvishavane Hospital, the largest referral Hospital in Zvishavane were HIV and AIDS related.

1.8 Statement of the problem

The main question this study intends to answer is, “In what ways are Mutambi Ward community members coping with the impacts of HIV and AIDS?” The specter of HIV and AIDS is threatening Africa, and has ravaged African communities. Studies increasingly show that the HIV and AIDS epidemic has had a significant impact on rural households and communities, and if present trends continue, its impact on development and on society will be devastating. The impacts of HIV and AIDS on rural communities are so vast and devastating, and how these communities cope with these impacts is what this study intends to assess. The study also explores how HIV and AIDS affect an agricultural project in a wetland area.

1.9.1 Study objectives

General objective

The general objective is to explore how individual households are coping with the impacts of HIV and AIDS in their daily lives.

Specific objectives

The specific objectives are the following:

- 1.1 To identify and assess the coping strategies adopted by the various households in light of the epidemic.

- 1.2 To explore the concept of home-based care among households with terminally ill PLHIV and how it works in Mutambi Ward.
- 1.3 To assess issues of disclosure, discrimination and stigma among community members in relation to HIV and AIDS and how they are dealt with.

1.10 Hypothesis

The study is based on the assumption that due to the impacts of HIV and AIDS in Mutambi Ward, the community has devised strategies to help them to cope effectively with the impacts of HIV and AIDS. The study is being conducted in an area with a Vlei project that benefits 42 households. A Vlei provides an alternative productive source of income to these households and the study assumes households in this project can cope better than those that are not because of the alternative sources of income.

1.11 Justification

The rationale for the decision to devote this research to an examination of the ways in which Mutambi Ward community has coped with HIV and AIDS is multifold. HIV and AIDS is a major killer of universal concern to governments of countries in Sub-Saharan Africa. The many years of investment in preventive and treatment measures have not yet resulted in significant declines in HIV and AIDS, mortality and morbidity. If anything, the problem is getting worse as the region's capacity for the provision of basic social services declines in tandem with a progressively weakening regional economy. The contribution this study makes towards this area of concern is that it will highlight the magnitude of the challenge facing communities, particularly the care giving role, stigma, discrimination and disclosure issues. This will inform countries on the extent to which these communities have succeeded or failed in addressing their own development problems, HIV and AIDS being the major drawback.

The relationship between national development and HIV and AIDS is complex. HIV and AIDS do not only feed on poverty, but also fuels poverty. About 10 percent of the world's population is found in Sub-Saharan Africa, but 70% of all globally infected persons with HIV and AIDS are in this region. Of the 33.2 million people living with HIV and AIDS globally, 70% of this figure is in Southern Africa and approximately

2.5 million new infections were recorded in Southern Africa in 2007 alone (<http://www.avert.org/worldstats.htm> 11.02.2006). HIV and AIDS cause immense human suffering and account for a huge loss of productive time. The disease imposes a heavy burden on the health services and caregivers. For these reasons, HIV and AIDS deserve prioritization in every major research effort.

HIV and AIDS is highly debilitating, fatal, disempowering and the impacts in all sectors of life have been devastating. The social, medical, financial characteristics of HIV and AIDS, pose great challenges to communities. Although a lot of research has been done in the areas of prevention, mitigation, impact and management of HIV and AIDS; much more needs to be done in view of their escalating impacts on the lives of communities.

It is this study's humble submission that social research will contribute in explaining how individuals, households and communities are coping with HIV and AIDS on a daily basis. This will help in contributing in the fight against HIV and AIDS.

CHAPTER 2

2.0 Literature review

2.1 Introduction

This chapter seeks to highlight the notion of ‘coping strategies’ in relation to HIV and AIDS. In everyday English, coping is dealing successfully with a difficult or challenging situation. For example, after a disaster or other major setback, a household, community or nation is regarded as ‘coping’ if it is able to regain its former standard of living, or even surpass it. A strategy is a general plan or set of plans intended to achieve something, especially over a long period of time. It is assumed therefore that all households have plans of some sort, which are designed to cope with the adversity. When a household or community has coping strategies, it has the *capacity* to effectively deal with a challenging situation and regain or surpass its former standard of living. Such capacity may be influenced by a variety of factors, among them the possession and application or utilisation of appropriate knowledge, skills, financial and material resources, etc to confront and overcome challenges or adversity.

Use of the notion ‘coping strategies’ in attempting to explain household responses to the impacts of HIV and AIDS gained currency in the late 1990’s when HIV and AIDS threatened and claimed lives of hundreds of thousands if not millions of people particularly in Southern Africa. Before this, the term ‘coping strategies’ was used to explain households’ responses to famines among others (Corbett, 1988, De Waal, 1989, Rahmato, 1991, Devereux, 1993:298). The advent of HIV and AIDS, however, has given the concept of coping strategies a new dimension, as it has now become widely employed in analysis of the impacts of the disease on households and their responses to it (Topouzis, 1999:32, UNAIDS 1999:137). Analyses of the effects of AIDS-induced morbidity and mortality on rural livelihoods, particularly in Africa have gathered pace in the last two decades. An understanding of ill health and coping strategies in rural livelihoods is essential at both theoretical and policy levels. However, the tendency to analyse many of the effects of the AIDS epidemic under the rubric of coping strategies needs critical appraisal.

This chapter therefore explores responses of individuals, households, communities and nations towards HIV and AIDS. It also presents literature on disclosure, stigma and discrimination in relation to HIV and AIDS. Most of the literature relates to Africa. With 70% of the world's HIV and AIDS cases being in Southern Africa and with the assumption that by 2025, 55 million Africans will die earlier than they would in the absence of AIDS, there is great need to explore HIV and AIDS in the context of the African setting. Concentration is also given to the rural setting because more than two thirds of the populations of the 25 most affected African countries live in rural areas.

2.2 The impact of HIV and AIDS in Southern Africa

An overview of the impacts of HIV and AIDS on different sectors will be given for a fuller appreciation of coping strategies. Many countries in Southern Africa are failing to bring the epidemic under control. Nearly two-thirds of the world's HIV positive people live in Southern Africa, although this region contains a little more than 10% of the world's population. There is a significant risk that some countries will be locked in a vicious cycle, as the number of people falling ill and subsequently dying from AIDS has a tremendous impact on many parts of African society, including demographic, household, health sector, educational, workplaces and economic aspects. At the moment, the worst affected countries in Southern Africa are Swaziland, Botswana, South Africa and Zimbabwe. HIV and AIDS have a widespread impact on many parts of society (<http://www.avert.org> 02.08.2005).

2.3 The impact on the health sector

Health-care services face different levels of strain, depending on the number of people who seek services, the nature of their need, and the capacity to deliver that care. In Zimbabwe, since 2003 to 2007, over 70% of all hospital admissions were HIV and AIDS related cases.¹ Hospitals are full to capacity in Zimbabwe at all times and yet there is very little these hospitals can do for the PLHIV. In Zimbabwe, terminally ill PLHIV were largely being referred to home-based care programmes, where PLHIV were said to be able to die in dignity (Baylies, 2003:374). This is because most hospitals have no drugs or other resources that they can use for treatment of opportunistic infections. Hospitals were largely depending on community Home

¹ Ministry of Health and Child welfare (MOHCW) 2007

based care programmes and worked with these particularly in training facilitators of the home based care programme and also referred PLHIV to these programmes.

2.4 *The economic impact*

Through its impacts on the labour force, households and enterprises, HIV and AIDS can act as a significant brake on economic growth and development. Besides the human cost, HIV and AIDS is having deep effects on Africa's economic development. In turn, this affects Africa's ability to cope with the epidemic. The impact of HIV and AIDS on the economies of African countries is difficult to measure. The economies of many of the worst affected countries were already struggling with development challenges, debt and declining trade before HIV and AIDS started to affect Africa. It is commonly believed, however, that together with other factors, HIV and AIDS have had a devastating effect on many countries economies.

Although the HIV and AIDS epidemic may affect overall economic growth, its economic consequences are more often considered in terms of their impact on household poverty, on the economic success of firms, and on government revenue and expenditures. Studies show economic setbacks in households that have experienced an AIDS related death or that have a family member(s) suffering from HIV related chronic illnesses. An adult illness or death leads to a loss of household productivity and income. Expenditures for medical care may increase substantially, especially after the development of AIDS. Funeral and mourning costs often consume a major portion of family savings, leaving the household ill equipped for the future Hanson 2005:68. A 2003 study in eastern Zimbabwe looked at the consequences for households of adult terminal illnesses and death. About four out of five of those who died were primary household income earners and three out of five lost their jobs during their illness (Human Development Report 2003). In addition, one in seven caregivers had to give up employment to provide care for the sick family member, and about one in four households had to relocate soon after death of a sick family member (Ministry of Health and Child Welfare, 2004: 41).

2.4.1 Agriculture and food security

Zimbabwe frequently suffers from serious drought and food shortages. This situation is aggravated by the HIV and AIDS epidemic. The situation is worse in rural areas. Rural areas are home to 51% of Zimbabwe's population, and about 21% of the adults are HIV positive. The number is further increased by those who get ill whilst they are in the urban area and decide to go to the rural areas for care and support during the terminal stages of their illness. The chronic illnesses that accompany deterioration of the immune system deplete household assets, reduce labour, and lead to reduced crop production. In Zimbabwe, one survey found that agricultural output declined by nearly 50 percent among households affected by HIV and AIDS illnesses and deaths (Human Development Report 2003). Frequent funeral attendance also affects land utilisation and agricultural productivity (Ministry of Health and Child Welfare, 2004: 32).

2.5 The impact on households

The toll of HIV and AIDS on households can be very severe. Although no part of the population is unaffected by HIV, it is often the poorest that are the most vulnerable to HIV and AIDS and on whom the consequences are most severe. In many cases, the presence of AIDS means that the household will dissolve, as parents die and children are sent to relatives for care and upbringing. A study in Zambia revealed that 65% of households in which the mother had died had dissolved. But much more happens to a family before this dissolution occurs: HIV and AIDS strip the family of assets and income earners, further impoverishing the poor (Katowa, 2005: 68).

It was documented in South Africa that already poor households coping with an HIV sick member were reducing spending on necessities even further. The most likely expenses to be cut were clothing (21%), electricity (16%) and other services (9%). Falling incomes forced about 6% of households to reduce the amount they spent on food and almost half of households reported having insufficient food at times. The same was noted in Botswana, it is estimated that 20% of rural families have reduced their agricultural work or even abandoned their farms because of AIDS (<http://www.avert.org/safricastats.htm> 25.10.09).

Household income and economic impact on households

HIV and AIDS are contributing to household poverty. Studies in Zimbabwe showed economic setbacks in households that have experienced an AIDS related death or that have a family member suffering from HIV related chronic illnesses. An adult illness or death leads to a loss of household productivity and income. Income for medical care also increases substantially after the family member has developed AIDS.

The household impacts of HIV and AIDS in the household begin as soon as a member of the household starts to suffer from HIV related illnesses. If the main breadwinner dies first, his/her illness leads to a loss of income when they are unable to work. Household expenditures for medical care may increase substantially. Other members of the household may miss school or work less in order to care for the sick member. When eventually HIV leads to AIDS and subsequently to death, the impacts are even more severe. There will be more permanent loss of labour, which may mean less labour for the farm or loss of family income or remittances. Health care costs also mount dramatically in the final stages of AIDS. An AIDS death can shift a household from poverty to extreme poverty. Of course, if one member of the household dies of AIDS the other parent may also be infected and die within a few months or years. Studies in Zambia, Tanzania, Ethiopia, and Uganda have documented the tremendous burden of loss of income, large health care expenditures and consumption of savings to pay for funeral and mourning costs. In many cases children are removed from school in order to save educational expenses and increase household labour. The result is a severe loss of future earning potential (National AIDS Coordination Programme 1998:39).

2.6 The impact on children

It is hard to overemphasise the trauma and hardship that children affected by HIV and AIDS are forced to bear worldwide. Not only does HIV and AIDS mean children lose their parents or guardians, but sometimes it means they lose their childhood as well. Poverty and economic hardships intensify the vulnerability of children (Zimbabwe Human Development Report 2003: 89). As parents and family members become ill, children take on more responsibility to earn an income, produce food and care for family members. It is harder for these children to access adequate nutrition, basic

health care, housing and clothing. Fewer families have the money to send their children to school.

In Africa, often both parents are HIV positive. This has resulted in AIDS in Africa orphaning more children than anywhere else in the world. Also many children will be part of a generation to be raised by their grandparents or left on their own in child-headed households. As projections of the number of AIDS orphans rise, some calls have been heard for an increase in institutional care for children. This solution is not only expensive but also detrimental to the children. Institutionalisation stores up problems for society, which is ill equipped to cope with an influx of young adults who have not been socialised in the community in which they have to live. There are other alternatives available. An example is the approach developed by church groups in Zimbabwe, where they recruit community members to visit orphans in their homes where they live either with foster parents, grandparents, other relatives or in child-headed households.

The capacity of a household to withstand HIV and AIDS shock and stress depends on pre-existing vulnerability of the farming systems to labour shortages and other inputs. This in turn is a factor of rainfall distribution, relative land availability, flexibility of genders roles/ wider social support network. Pre-HIV resource availability and savings also have an impact as they are a good indicator of resources available for caring expenses. Also, the number and role of people dying in household production and the role of non governmental organisations have a contributory impact to a household's response to the impacts of HIV and AIDS.

2.7 Effect of these levels of infection

Over and above the personal suffering accompanies HIV infection wherever it strikes. Worldwide, HIV threatens to devastate whole communities, rolling back decades of progress towards a healthier and more prosperous future. Southern Africa however faces a triple challenge of colossal proportions. First challenge being to bring health care, support and solidarity to a growing population of people with HIV-related illness. Secondly, Southern Africa should be able to reduce the annual toll of new HIV infections by enabling individuals to protect themselves and other individuals. Lastly, Southern Africa has to cope with the cumulative impact of over 17 million

AIDS deaths on orphans and other survivors, on communities, and on national development.

The impact has been most severe in farming communities (Rugalema, 2000:583). Farm households coping with HIV and AIDS sell assets such as livestock, equipment or land to support ill family members and pay for funeral expenses. Time devoted to care, funerals and mourning of family members with AIDS reduces productivity and jeopardises households' ability to produce and purchase food (Lamprey et al 2006: 17). Moreover, important knowledge and skills are lost as deaths mount among the agricultural population. Women in agricultural households are particularly hard hit since they often provide the primary labour for farming, but must increasingly spend their time caring for the sick family members.

For the moment, HIV prevalence rates are declining. However, there are still more newly infected individuals joining the pool of people living with HIV every year. As people infected years ago succumb to HIV related illnesses (average survival in absence of antiretroviral therapy is estimated at around 8-10 years), mortality from AIDS is increasing, and the long-awaited rollout of AIDS drugs has still not happened in many places. HIV prevalence varies considerably across the continent, ranging from less than 1% in Mauritania to almost 40% in Botswana and Swaziland. Worldwide, AIDS killed approximately 2.0 million people in 2007 alone (UNAIDS 2007). In the coming years, unless there is far broader access to life prolonging therapy, and provided that new infections do not start rising again, the number of surviving HIV positive Africans can be expected to stabilize and finally shrink, as AIDS increasingly claims the lives of those infected a long time ago.

The extent of the epidemic is only now becoming clear in many African countries, as increasing numbers of people with HIV are now becoming ill. In the absence of massively expanded prevention, treatment and care efforts, the AIDS death toll on the continent is expected to continue rising before peaking around the end of the decade. This means that the worst of the epidemic's impact on these societies will be felt in the course of the next ten years and beyond. Its social and economic consequences are already being felt widely not only in health but in education, industry, agriculture,

transport, human resources and the economy in general, (<http://www.avert.org> 26.03.2005).

2.8 Household responses and coping mechanisms

The capacity of a household to withstand HIV and AIDS and stress depends on pre-existing vulnerability of the farming systems to labour shortages and other inputs. These, in turn, are a factor of rainfall distribution, relative land scarcity, flexibility of gender roles, wider social support, pre-AIDS resource availability and the number and role of people dying in household production (Tumushabe 2004:256). According to a study carried out by Makerere University, if rainfall patterns were favourable, if land was available in abundance, when gender roles are flexible, and where resources are available for inputs, then a household affected by HIV and AIDS was likely to cope more than a household that had the above in limitations. The study conducted in three rural districts of Uganda also noted that the presence of a wider social support network was also a positive factor. A variety of coping mechanisms were also highlighted by studies conducted in rural parts of Uganda.

Intra-household relocation of resources, including removal of children especially girls from school, increased reliance on orphan labour, relying on the elderly, children and wider social networks, and remittances from outside the household itself were some of the coping mechanisms frequently adopted. Also noted were shifting composition of livelihood bases from labour intensive to less labour demanding, from cash to subsistence, from vegetable and relishes to carbohydrate-rich foods, from wide range to narrow range of crops and animals, diversification of production base including adoption of apiculture and off-farm income generating activities and replacing household labour with hired labour. Less reliable coping strategies were also noted and some of them include, piecework, off-season farming, compromising critical land conservation and soil protection, sale of household assets including land, reduction in quality, quantity and variety of food and withdrawal from commercial to subsistence activities (Tumushabe 2004:378).

Gabriel Rugalema 2003 is not a new name to studies concerning HIV and AIDS. He wrote an article entitled “Coping or struggling? A journey into the impact of HIV and AIDS in Southern Africa”. According to him, different communities have responded

differently to the impacts of HIV and AIDS. He went on to say when it came to loss of labour, the following were adopted by some communities: sale of labour, co-operative labour, a decrease of acreage, neglect of cash crops, intensification of use of child labour, withdrawal of children from school, working long hours and crop substitution. Rugalema also highlighted that households affected by HIV or AIDS had a shortage of food and employed strategies to cope with this shortage and these include; a decrease of household size (other members foisted out/dissolution), smooth consumption of food (eat less quantities and eat low quality food), and casual labour which involved working for food. Finally, he looked at how HIV and AIDS had resulted in loss of income and found out that households had responded by doing the following, dependency on credit loans, forego essential services like school, medical care, and clothing, decrease consumption of purchased food stuffs, petty trade and casual labour, begging and withdrawal of children from school).

Several studies have also been carried out on how households are coping with the impacts of HIV and AIDS. The economic impact of HIV and AIDS is long term, impacting through the family network. In South Africa, planners are focusing on building the economic resources of households and on supporting the creation of community level safety nets. This is so that households that are poor are provided with economic support before they are worst hit by the impacts of HIV and AIDS Matthew Leake 2007. In the end these households are able to slow their economic descent and buy themselves enough time to devise adequate coping strategies. A study in Uganda 1996 revealed how six districts in the country were coping with patient care, orphan hood, widowhood and burial, marriage and funeral ceremonies all as a result of HIV and AIDS. HIV and AIDS has had significant economic, psychological, and social effects Marta Zaccagnini 2007.

Self-Help

There are methods available for the average person to deal effectively with HIV and AIDS. This is not 'positive thinking'; it is realistic hope, based upon solid scientific research (Orr, 2003). People who live with HIV or AIDS can play an important role in their own care. The value of self-help lies partly in direct health benefits and partly in psychological benefits. Being passive and dependant and feeling helpless reduces self-esteem and easily leads to depression. Self help includes looking after one's own

physical health and well being and seeking emotional support and practical ideas from others, and is particularly helpful for those who have recently learnt they have the virus, especially when family or friends have not been told of the diagnosis or when they have not been supportive. Self-help is a very important stage in helping a person infected with HIV to cope. How a person accepts their status usually determines the extent to which they will be able to help themselves cope as well as how 'others' will help them cope (Orr, 2003).

2.9 *Community initiatives*

Different forms of community initiatives to help households' agricultural production activities and other capital input requirements that have been in existence in many African societies are being promoted because of their mitigating role. Examples of such initiatives include labour-sharing clubs, draft power clubs, community seed banks, Community labour sharing is a common community coping response adopted by communities to help support affected households in many communities in the sub region. Labour-sharing groups facilitate land preparation, weeding or harvesting, thereby helping reduce total cultivation time and enabling a greater number of households to overcome problems of timeliness associated with land preparation, planting and harvesting. Labour-sharing clubs have been reported to be effective in relieving HIV and AIDS related labour shortages in some communities in Malawi and Zambia (Barnett and Grellier, Economic Commission for Africa, 2006:13).

Support and mitigation

Support and mitigation is usually in the form of social support and self-help groups. In response to increasing household food insecurity largely due to AIDS, Africare, a private American NGO, launched the Small-Scale Agricultural Mechanization Promotions Project (SAMEP) in Zambia. The project promotes the following short-maturing seeds, e.g. katumani maize, sunflower, sorghum and sesame; nutritious leguminous crops, e.g. cowpeas and mung beans; conservation farming; seed multiplication initiatives as income-generating projects (surplus seed is sold to other organizations e.g. World Vision and Oxfam); labour-saving technologies, e.g. oil presses, groundnut lifters; livestock credit in-kind activities; HIV and AIDS Information, Education and Communication (IEC) initiatives using drama and radio;

income-generating projects for rural youth, e.g. vegetable production, dairy farming and bakeries, together with training in requisite business skills; youth information centres, where information on various issues is provided, including reproductive health and STIs. The overall result of such a project is the promotion of support de-stigmatisation, openness and support to PLHIV (Africare Zambia 2006).

2.10 Patient care

Care for terminally ill people such as HIV or AIDS clients is particularly difficult in resource poor countries (Shephard, 2000:65). Terminally ill clients would like to die with dignity and in peace but care providers often lack the support they need to relieve pain and distress of people nearing death. Traditional African society relied on women as principal carers for the sick (Ntozi, 1996a:346). However, with the advent of the HIV and AIDS pandemic, in Uganda, all members of the family and clan are all expected to assist in nursing care and treatment. The usual method of AIDS patient care is seeking preventive and curative treatment from health units (Mann, 1996). In Uganda, AIDS care and treatment are given in selected medical units scattered throughout the country (STD/AIDS Control programme, 1998:7). However, with the increasing number of PLHIV, lack of space for admissions and lack of a cure for AIDS, the affected families have sought other means of care and treatment ranging from traditional healers, spiritual healing and self medication at home. Traditional healers are however more popular than the other two alternatives. Traditional healers include herbalists who deal with day-to-day treatment of PLHIV, and diviners who seek underlying causes <http://medical.bizcommunity.com/Article/196/149/40223.html> 14.10.09. Some believe in them to the extent that they abandon the ART treatment prescribed to them by their physician (Lubasi Mutafela, Times of Zambia 2005). Home-based AIDS care by the patient's relatives, friends, medical personnel and social workers has become one way of coping in which PLHIV are cared for at home. Health workers who have been trained in basic health care, AIDS education and counselling visit households with PLHIV and help these households cope with most HIV and AIDS related activities <http://aidsaction.info/cwc/section4.html> 26.07.2009. Other non-governmental organizations such as The AIDS Support Organization (TASO), foreign NGO's, and religious missions also give support to these households in the form of basic food stuffs (IRIN Plus News, March 6, 2008).

(Ruth Evans 2006) in her studies in Tanzania revealed how 20 households in Arusha were coping with patient care. Reasons why they have coped so well included the fact that they had cooperated with other relatives, neighbours, and other members of the community so well and were getting a lot of support from them; they had also received support from several religious organizations who provided support in the form of drugs, food, medical fees, medicines, gloves, spiritual support and even assistance with domestic work. Of great help to care providers according to this study is treating PLHIV with respect, encouraging them and being close to them (Nnko, Chiduo, Wilson et al., 2000). The study however revealed that the responsibility of the care giving role still largely falls on women since only six (6) out of the twenty-one (21) carers were male. The study also revealed that quality of care for patient improves subsequently as a result of previous experience, even in the absence of professional counselling. In South Africa, women's organizations have advocated for effective coping strategies for caring for people living with HIV and AIDS, in a manner that ensures that women do not bear a disproportionate burden of caring for those who are HIV positive, neglecting their own health and becoming further economically marginalized. This will involve educating men on how they can contribute in HIV care and educating them that the burden of the care giving role has largely fallen on women and now men have to take up the task Dr Clarence Hall et al 2006.

Orphan care

The extended family had an obligation to assist orphans in the old days, various relatives mostly from the paternal side would take care of them (Urassa et al., 1997:74). If one parent survived, he or she could take care of the children. In the case of widows, successors to the deceased husband, if they came from the husband's family, were the ones responsible for the care of the orphans. Children's homes also used to look after homeless children. But now these homes cannot meet all their objectives through lack of funds and overcrowding. Recent studies have shown that the emergence of HIV and AIDS has resulted in orphan care by mainly relatives from the extended family (Aspaas, 1997; Nnko 2000a:396). In Zimbabwe, the obligation of caring for AIDS orphans has now shifted to maternal relatives, away from the paternal relatives whose responsibilities it was in the past (Foster, 1998:65). Studies

by UNICEF in rural Zimbabwe and Uganda have shown that orphans in rural areas are usually taken up by the extended family, usually by the maternal relatives more than the paternal relatives. These orphans are usually taken care of by grandparents who are usually so old that, under normal circumstances, they themselves need to be cared for. These families are usually supported by NGOs with food, clothes and school fees. In Uganda, some communities have also assisted these orphans by building homes where they can live with relatives (Gapere, 1995:45).

Widowhood

Traditionally, the problem of widowhood in many African societies was solved by inheritance of widows by the man's relatives. In countries like Kenya, Mali, Zimbabwe, Sierra Leone, Zambia and Namibia and Rwanda, widows were expected to remarry within the husbands' extended family (Ntozi, 1996:347). Widow inheritance is regarded as a social obligation to ensure that care is given to the widow and orphans and sexual intercourse is an essential component of widow inheritance (Ntozi, 1996:349). In an era of HIV and AIDS, the custom of widow inheritance in Uganda has declined because of the risk of HIV infection to the inheritor. In Uganda, in most cultures now, no relative has an obligation of inheriting a widow. Most widows become household heads in their own right and are helped by paternal family in day-to-day expenses (Gapere, 1996:355). Migration is usually a response by widows, as noted by several studies. The resultant option is remarrying. Migration has therefore become a risky behaviour, which facilitates the spread of HIV. AIDS widows usually migrate in search of better livelihood, obtain better services, find knowledge of physicians and escape discrimination or to remarry.

Burial and funeral ceremonies

In many African societies, burials and mourning for the dead took several days among affected families. Preparation and performance of funeral rites lasted for long periods. Sexual intercourse with non-relatives attending the funeral took place so as to ensure replacement of the dead (Ntozi, 1996:334). The AIDS pandemic has brought many deaths in the Ugandan population. This has changed ceremonies relating to deaths, burials and last rites. These ceremonies are shorter because the frequency of burials has meant they must be less costly and be followed by shorter

mourning periods (Ntozi, 1996:336). Community members in one district, Rakai, changed their mourning days from four days to one day in order to tend to their crops (Obbo, 1995:12). All these changes related to death reflect the realities of coping with the impacts of HIV and AIDS.

2.11 Coping strategies adopted

2.12 *Home-based care as a coping strategy*

Home-based care programmes are a very common response and a major coping strategy in most communities. Their objective on paper is to provide vital complementary services to the terminally ill without substituting institutional care. They are seen as a way of reducing congestion in hospitals and reducing hospital expenditure in the face of high numbers of PLHIV with incurable and chronic illnesses. Overseas from whence this strategy was learnt, PLHIV are discharged but are monitored by the hospital which sends professionals like nurses, and physiotherapists on home visits to monitor the patient and satisfy themselves that his/her condition is stable and the house environment conducive to patient's welfare. They administer drips, intravenous feeds and maintain PLHIV's files at the hospital (Baudin and Chambre, 1996:21). In third world countries this does not usually happen though. PLHIV are discharged to be cared for by people with rudimentary knowledge of caring for PLHIV with complicated and chronic conditions such related to HIV and AIDS.

In Zimbabwe, home-based care participants work purely on a voluntary basis. However, some NGOs give a 'retainer' allowance. Often, they visit the sick, help with health education for the sick and immediate family members who care for them, demonstrate how the sick should be cared for, and encourage the sick to take their medications. They also help with patient care. With the numbers of the sick increasing, home-based care is becoming predominantly a full-time occupation which takes time and attention from members' livelihoods.

2.13 *Community orphan care programs*

Increasing deaths due to the pandemic have gradually led to an unprecedented increase in the number of orphaned children, leading to the emergence of child-

headed households with no resources, limited capacities to mobilize them, no social networks and an inability on account of age to navigate bureaucracies to access available help. Most orphans are dispossessed of their parents' estates due to funeral rituals, which dictate that the estate of a deceased adult must be shared by his/her surviving relatives. Although this should include children, their age renders their claims to the estate easy to ignore. In many cases, these children are left in the care of elderly grandparents. Usually, the responsibility falls on grandmothers with limited abilities to mobilize resources to care for the children properly. Most grandparent-led households do not receive public assistance because of overwhelming demand for public assistance. For those that do receive it, it is so meaningless that it does not meet any of their needs, from education, food to healthcare.

Because of the unprecedented levels of poverty of affected children, communities are mobilizing resources to care for them. In Chimanimani district (Manicaland province), for instance, women formed groups within their wards and villages in which they cared for orphaned children. They had 'volunteer mothers' who supervised orphans but left them to live in their deceased parents' homes (Mare, 2001:12). They noticed that, where orphans were adolescent girls, sexual abuse and incest occurred, leading to pregnancy because of lack of parental supervision. They devised a code of conduct and tried to tell the children about growing up in keeping with local practices.

In Masvingo, and Mwenezi districts, communities there also had locally initiated orphan care programs, which were later donor funded in the early 1990's. The initiatives also incorporated local traditional leaders who mobilized the people to contribute money per household to go towards orphan care. The money was used to pay fees, uniforms, food, and clothing. The communities organized themselves into committees that ran the program (Matshalaga, 1997:35). They also identified children in need who were assisted and ran income-generating projects such as poultry, piggery, and a few others to help bolster funds collected. In addition, donors such as United Nations Children's Fund (UNICEF) donated to some of the initiatives.

2.14 Marriage

In Uganda, in former times, marriage was a respected institution and parents played a big role in the selection of their children's partners (Ntozi, 1996:361). Polygamy was popular in African societies: a man with numerous wives was highly respected by the community and was usually seen as very wealthy. Several changes in marriage closely connected with the AIDS epidemic have taken place. Some of the coping mechanisms that have been reported in marriage in the AIDS era include delayed marriages, stability and fidelity in marriage, separation and divorce when one of the spouses is unfaithful and separation of beds if one of the spouses is promiscuous (Ntozi, 1996:287) as it is well known that polygamy compounds the AIDS problem. Some people are opting for HIV testing before they commit themselves to any sexual relationship. These people usually have a commitment to marriage or stable sexual relationships.

2.15 Religious organizations' responses

Christianity-Based Responses

Although Christianity is the dominant religion, 73% of Zimbabweans practice it, (Mhloyi, 2003:25), many people practice it side by side with local traditional religions. There are also many versions of Christianity, with some churches overtly borrowing from traditional religious practices such as divination, witch hunting and healing. Consequently, responses have varied across the board. Older churches have mission hospitals in rural areas and have been instrumental in healthcare delivery in the country. These hospitals have also been at the forefront in the response to HIV and AIDS in rural areas. Many have Community Home Based Care (CHBC), peer educators and orphan care programs affiliated to them. Some also have Voluntary Counseling and Testing (VCT's) (Murambinda Mission Hospital 2002 and Chidamoyo 2002:98)

Syncretic churches, on the other hand, do not have hospitals per se, but offer alternative healing services through "faith healing" which comprises 'laying of hands', 'holy water', prophecy and divination. These churches believe they can heal HIV and AIDS opportunistic infections. They are on the increase in Zimbabwe. Many people who are sick and desperate end up at these churches in search of a cure or

some respite. Some of them discourage the use of Western medicine and traditional medicine, calling their followers to have faith and use the 'holy water' and other such items that are given by the leaders. Some use unprotected sex as a form of internal cleansing, thereby increasing the risk of spreading HIV. The much publicized recent court conviction of a prominent healer is a case in point (the case of Madzibaba Nzira, a well known leader of a sect who was found guilty of raping an unspecified number of women for many years under the pretext that they were being healed).

2.16 African Traditional Religious Responses

Traditional religious practitioners have been slow in their response to HIV and AIDS. Their methods of medical practice are generally held in secret and mystery yet their rituals do not shy away from sex where so deemed by their healers. It is after all because of some of their recommendations that some terminally ill men have sex with prepubescent girls because of the belief that they will be permanently cleansed. Given that many people resort to traditional healers when desperate as they often are when infected with HIV and are already at the AIDS stage, this state of affairs has also fuelled the spread of the disease.

Often, traditional healers attribute incurable diseases to unhappy ancestral spirits or witchcraft Munthali A. C 2002. This fuels denial of HIV and AIDS and negates any work done by HIV and AIDS activists encouraging openness. Traditional healers recommend appeasing the ancestral spirits through ceremonies and rituals whose effect is divesting the family estate. Where witchcraft is diagnosed, people spend on charms and rituals to fend off witches and other dark forces. Some of the latter are in the form of skin incisions (which lead to bleeding) made with one razor blade on all members of the family or community. Medicines are later inserted into these incisions for protection. Although traditional healers have associations, not all practitioners are registered so that whatever training the organizations receive does not filter to all practitioners. In any case, there are many other practitioners, as presented above, who do not consider themselves traditional in the sense of using herbs. As such, they remain in a grey area and HIV and AIDS prevention blind spot (Obayo, 2004:67).

2.17 Women's groups and non-governmental organizations' responses to HIV and AIDS

The strategic framework notes women's vulnerability to HIV and AIDS but also notes the existence of a vibrant women's movement as an opportunity for women's empowerment and HIV and AIDS prevention. Women's organizations focus on gendered aspects of vulnerability that seek to empower women to prevent infection through condom negotiation skills and economic empowerment to limit the need for transactional sex. It is also on women's shoulders that the burden of the care for the sick and orphaned children falls. Women do the care giving work as individuals or as groups, often working without pay. They work as volunteers through churches, local community based organizations, Non governmental organizations as well as government initiatives. Women also dominate AIDS service organizations (ASO) as infected and affected people seeking mutual support from other similarly situated people. Men generally shy away from such mutual aid organizations.

2.18 Community Responses to HIV and AIDS

The community-based response has also relied too much on voluntarism, which often leads to high turnover of 'staff', leading to low sustainability of programs (Government of Zimbabwe, 1999a). Where CBO's are affiliated to mission hospitals, they rely on personnel who volunteer to do HIV and AIDS work as an 'extra-work'. Consequently, burnout is high and many such dedicated persons end up giving up since their effort goes unrewarded. Voluntarism is a double-edged sword which on the one hand assumes that communities and individuals are dedicated to the task at hand, but on the other hand also gives the impression that the government and donors do not take HIV and AIDS work seriously and as worthy of remuneration. Given a generalized epidemic, there is the real concern that there are no resources to recruit a huge labour force for the foreseeable future.

Community responses also include AIDS service organizations which give support to the infected and affected, helping them to deal with infection and to mitigate the effects of HIV and AIDS. They operate at provincial level, providing HIV and AIDS awareness information using the Information, Education and Communication (IEC) strategy and also distributing condoms. They also run community home-based care and orphan care programs.

Studies have shown how community support systems are very instrumental in the fight against HIV and AIDS. In one study in Igoma, Tanzania, community religious groups were shown to be putting an effort in the care of PLHIV. Religious organisations in Igoma provided spiritual support, money, medicines, and gloves. They also assisted affected families with domestic work. The Roman Catholic Church in the ward was reported to have carried out several regular visits to PLHIV, provided drugs, and given spiritual support. A number of PLHIV were recorded to have received support from religious organisations. A common feature of these organisations was that they were self supporting. Their strength was that they were there at the local scene and easily understood and identified with the families they worked with (Nnko et al., 2000:533).

2.19 Informal grassroots community organizations

To help cope with the impact of HIV and AIDS in their communities, Africans have established a wide range of social support activities. These activities serve to share the burden of increasing workloads. Sometimes the community itself initiates them, or they may be started and supported by outside agencies, such as government, NGOs or religious institutions. This wide range of strategies includes loans and savings clubs, shared child care, labour-saving clubs, funeral funds or burial societies Mutangadura G et al 2000.

These are communal social support systems and many households affected by HIV and AIDS are dependant on these for social support (Tumushabe, 2004:48). Some countries of note Zambia and Uganda have put up measures to prevent HIV and AIDS affected households from sliding into destitution and risk of starvation by putting in place poverty-alleviation strategies. These include micro-saving operations, management cooperatives and community informal credit schemes. These are only meant for households affected by HIV and AIDS.

2.20 Burial societies

Burial societies provide mutual assistance to members in rural areas in the event of death and illness. They offer a measure of financial security when a family member dies; they also provide some of the other social needs of their members. Burial

society members might also devote part of their time to helping bereaved families by cultivating their fields. Burial societies work in different ways; sometimes there is spontaneous giving at the time of the death, or people make contributions over a period of time and at the time of the funeral the funds are made available. Burial societies have been very beneficial in most rural areas. The emergence of the pandemic has resulted in high deaths rates and this has been marked by an increase of funerals in most communities. This is particularly true in rural areas because some of those who die in urban areas are ferried to their rural areas for burial. Burial societies, as a result, have gone a long way in helping cushion households from burial expenses.

2.20 *Savings clubs*

Savings clubs and schemes are helping households affected by HIV or AIDS because most of them usually have unstable income patterns. Helping such households build savings allows for reduction of economic risks and for coping with AIDS-related expenses. These, in some communities, involve rotating savings and credit. United Nations Programme on HIV and AIDS (UNAIDS) cites various examples of spontaneous development of AIDS foci within conventional savings clubs. These include Tanzanian savings clubs which specifically target households affected by HIV or AIDS through assisting them with money, food, fuel, labour, and other items to assist those who are ill, assisting with burial costs and supporting subsequent income generation activities. Similarly in Zimbabwe, women have taken up the initiative of forming savings clubs that help children orphaned by HIV and AIDS. There are many variations of savings clubs. Some are community-initiated savings clubs. Generally, members hold a meeting to decide what they want to save for during a period of time, for example a year. They decide on their requirements for seed, fertilizer and insecticides. These supplies are then ordered in bulk and distributed to their targeted beneficiaries.

2.21 *Grain saving scheme: a case of Zimbabwe*

In the grain saving scheme the grain is produced for free through community labour. Contributions of seed and fertilizer are an integral part of the scheme, helping to ensure that the harvests are meaningful and can stretch a long way to assist households affected by HIV or AIDS (<http://farmradio.org/english/radio->

[scripts/73-1script_en.asp](#) 17.01.06). In most cases, the grain-saving scheme is administered by the local chief to ensure that all intended beneficiaries within the chief's area of jurisdiction are reached through a transparent system. For this reason, this scheme is called "Zunde raMambo" (Chief's communal grain store).

2.22 *International donor as a coping strategy*

International and bilateral donors are critical in a comprehensive response to HIV and AIDS because they offer expertise and resources. Multilateral organizations have been at the forefront of mobilizing the global community to commit itself in fighting HIV and AIDS. They have also provided aid to several countries. Currently, aid to HIV and AIDS has generally focused on HIV and AIDS awareness, condom distribution, Home based care programs and children affected by HIV and AIDS. Today, there is a Global Fund on HIV and AIDS that is offered to countries that meet certain criteria.

2.23 *Global response to HIV and AIDS*

From the time HIV and AIDS was diagnosed in 1981 in the US, worldwide responses to the disease have been observed to follow the same pattern-first there was denial, complacency, followed by panic and finally acceptance (Rabbow, 2001; Chambre, 1996). Time spent at each stage varies from country to country depending on availability of material resources, access to scientific knowledge and expertise, and a complex web of cultural issues. The panic that many governments find themselves in is a result of what Dr Mann the first head of the Global Program on AIDS (GPA) describes as "the backlash of complacency" (Tavanyara, 1992:6) or the effects of slow, weak and selective responses from the time when the disease was first discovered. In other words, complacency is an ally in the spread of HIV and AIDS (Zimbabwe Human Development Report, 2003).

2.24 *Africa's response*

A large percentage of the world's HIV and AIDS cases are in Sub-Saharan Africa. More than two-thirds of the population of the affected live in rural areas. HIV and AIDS is in rural areas, tearing families apart, destabilising communities, reversing the evolution of farming systems and rural livelihoods and economies.

In Africa, a by-product of the political liberalisation of the past few years has been a growth in associational life, the development of non-governmental organisations, grassroots and community-based organisations which address daily development issues and which are an essential complement to overstretched national governments (Goliber T 2007). In the context of the HIV epidemic, African NGO's and community-based organisations have been at the forefront of those organisations, which have encountered the challenges of HIV and AIDS with compassion and solidarity. Where governments were slow to act, these organisations have provided education, prevention, care, counselling and advocacy for the people living with HIV and AIDS. They have also championed home-based care for people living with HIV and AIDS, building on Africa's reservoir of the caring and community spirit.

2.25 *Zimbabwe: Responses of HIV and AIDS*

President Robert Mugabe has described Zimbabwe's response to HIV and AIDS as slow, weak and selective Government of Zimbabwe 1999a: 123. Despite talk of the need to implement a multi-sectoral response, the response has largely been medical driven by the health sector. The biomedical approach predominantly views HIV and AIDS as a problem of an infectious organism (the HIV virus) entering the body causing physiological imbalances and dysfunctions (opportunistic infections) leading to death. Its solutions focus on preventing the virus from entering the body and treating the imbalances and dysfunctions visited on the body as a result of the virus. It is curative and concerned with fighting microbes (Zimbabwe Human Development Report 2003: 124).

The Zimbabwean government recognizes the seriousness of the HIV and AIDS epidemic and acknowledges this in the Zimbabwe Millennium Development goals (MDG). Goal 6 states 'combat HIV and AIDS, Malaria and other diseases'. Target 7

states 'have halted by 2015 and begun to reverse the spread of HIV and AIDS'. The government further acknowledges the need for a development approach to controlling the epidemic. However, the priorities outlined in the MDG report have remained trapped in the medical response without providing any indication of the focused development strategy.

Supportive Environment

There has been an enhanced political commitment to the fight against HIV and AIDS, Malaria, Tuberculosis (TB) and other diarrhoeal diseases in Zimbabwe. In 1985, at the onset of the HIV and AIDS epidemic, the Government of Zimbabwe set up the National AIDS Coordinating Unit under the National AIDS Coordinating programme to address the challenge of the HIV and AIDS pandemic. It was through the National AIDS Control Programme that the National AIDS policy was produced and later, through an Act of parliament the National AIDS Council was established. Other policies include HIV prevention in the workplace and the Orphan Policy. In addition, a Cabinet Committee on HIV and AIDS was set up to focus on HIV and AIDS issues. In order to scale up the National response and to raise resources, a National Trust Fund was set up with funding from a 3% levy on personal incomes or personal incomes of formal sector employees. The government of Zimbabwe has also fostered strong partnership with various stakeholders and other development agencies in the fight against HIV and AIDS. The setting up of Voluntary Counseling and testing centers, provision of life skills education in schools, the piloting activities on the prevention of mother-to-child transmission and peer education programmes in the uniformed forces and parliament are all initiatives for combating HIV and AIDS.

The government has also listed HIV and AIDS as a priority for development. According to the government, reducing HIV transmission, through promoting behavioral change will be central to combating the epidemic. It is important to recognize that behavioral will not take place until strategies are put in place to address the current development vulnerabilities being experienced by the population. These vulnerabilities are primarily responsible for risky sexual behaviour, which underlies the epidemic. Thus designing and implementation of broad-based national poverty reduction strategies has become a national priority. Zimbabwe has also taken a stance in combating stigma and discrimination. Reconsidering the public health classification

of the disease will do this. Other measures in place include care and support for people living with HIV and AIDS, rights for children or young people infected or affected by HIV and AIDS, effective management of the national response to HIV and AIDS and Information, Education and communication about HIV and AIDS and STIs (Zimbabwe Millennium Development Goals Progress Report, 2004).

2.26 HIV and AIDS: Stigma, Discrimination and disclosure

All over the world, the AIDS epidemic is having a profound impact, bringing out both the best and the worst in people. It triggers the best when individuals group together in solidarity to combat government, community and individual denial, and to offer hope and reassurance as well as support and care to people living with HIV and AIDS. It brings out the worst when individuals are ostracized by their loved ones, their family and their communities, and when they are treated with discrimination, both at the individual and institutional levels. Positive and negative responses to HIV and AIDS may be exhibited as overt actions, or may take the more subtle form of attitudes and emotions. All these are a reflection of, or have an impact on, the coping capacities of individuals and groups of individuals. All over the world, HIV and AIDS PLHIV have been stigmatized and discriminated. HIV-related stigma and discrimination can be defined as a 'process of devaluation' of people either living with or associated with HIV and AIDS. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status UNAIDS 2003. Lastly, disclosure is defined as the act of revealing or uncovering <http://www.thefreedictionary.com/stigma> 24.10.09.

Stigma and discrimination

Stigma and discrimination related to HIV and AIDS are almost as old as the pandemic itself and, regrettably, often exist in health-care settings, homes and even at the workplace. Discrimination against people living with HIV or AIDS results in poor quality of care for those who are infected or ill (or suspected of being infected), frightens away potential clients in need of care, and undermines effective HIV prevention efforts by limiting individuals' access to and use of health care services. As HIV treatment programmes become increasingly available in resource-poor

countries, access to and use of these life-saving services will depend on the degree to which health facilities welcome and respect the rights of HIV positive clients.

From the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. HIV and AIDS have been shrouded by these social responses especially because from the beginning it was associated with members belonging to certain deviant social groups. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS. It goes without saying that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. Across the world, the global epidemic of HIV and AIDS has shown itself to be capable of triggering responses of compassion, solidarity, support, and many other nobler attributes of people, their families and communities. But the disease is also associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer countries of the south (Fassin, 2002; 9).

Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. homosexuals, injecting drug users, sex workers) may predate HIV and AIDS, the disease has, in many cases, reinforced this stigma. By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations. This is seen not only in the manner in which 'outsider' groups are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need. Stigma is a major obstacle to combating HIV and AIDS because it makes people avoid being tested for HIV status. Furthermore, stigma and discrimination further result in the spread of the virus because those who test positive do not disclose for fear of being isolated. Those who want to be tested also are not forthcoming because they see how those who have tested positive are being treated and so they would rather not know their HIV status. Stigma and discrimination also make people with HIV and AIDS more vulnerable to sickness and death because they are less

likely to seek appropriate medical care and psychological support, and are more likely to be denied services if they do seek them (Lampthey et al 2002: 26).

Why there is stigma related to HIV and AIDS

Traditional psychological approaches to stigma imply that it is partly or wholly a problem of individual ignorance. This implies that the silence can be broken around HIV and AIDS if people are given the facts. This is the rationale behind educational interventions for the general public to reduce ignorance and increase ‘tolerance’ of people living with HIV and AIDS. In an attempt to explain why education has not eliminated stigma, a number of researchers have developed a critique of the traditional approach to understanding and researching HIV and AIDS stigma (Stein et al., 2003a:9). They suggest that stigma is, instead, a complex social process linked to competition for power and tied into existing social mechanisms of exclusion and dominance. Although this critique of traditional psychological approaches is useful and valid, both theoretical approaches to stigma remain problematic. We need to be able to explain the functions or effects of stigmatization without resorting to functionalism (defining stigma in terms of discrimination), and we need to be able to understand the role of the individual in stigmatization without resorting to individualism (defining stigma as a problem of individual ignorance).

Stigma has come to mean almost anything people do or say that stands in the way of rational responses to public health campaigns on HIV and AIDS, or that restricts the access of people living with HIV and AIDS to employment, treatment and care, testing and a reasonable quality of life. HIV and AIDS stigma cannot describe the entire range of barriers to dealing with HIV or AIDS – making the concept too elastic does not help us to understand what causes these very different barriers, or to develop interventions to address them.

Factors that contribute to HIV and AIDS related stigma include HIV and AIDS, as a life-threatening disease, people are scared of contracting; the disease’s association with behaviours (such as sex between men and injecting drug-use) that are already stigmatised in many societies; people living with HIV and AIDS are often thought of as being responsible for becoming infected; religious or moral beliefs that lead some

people to believe that having HIV and AIDS is the result of moral fault (such as promiscuity or 'deviant sex') that deserves to be punished.

Sexually transmitted diseases are well known for triggering strong responses and reactions. In the past, in some epidemics, for example TB, the real or supposed contagiousness of the disease has resulted in the isolation and exclusion of infected people. From early in the AIDS epidemic, a series of powerful images were used that reinforced and legitimized stigmatisation. Some of these include; HIV and AIDS as punishment (e.g. for immoral behaviour), HIV and AIDS as a crime (e.g. in relation to innocent and guilty victims), HIV and AIDS as war (e.g. in relation to a virus which needs to be fought), HIV and AIDS as horror (e.g. in which infected people are demonised and feared), HIV and AIDS as 'otherness' (in which the disease is an affliction of those set apart) <http://www.avert.org/aidsstigma.htm> 16.04.2003.

Together with the widespread belief that HIV and AIDS are shameful, these images represent 'ready-made' but inaccurate explanations that provide a powerful basis for both stigma and discrimination. These stereotypes also enable some people to deny that they personally are likely to be infected or affected. Disease stigmatisation associates negatively-defined behaviours or attributes (for example, promiscuity or lack of cleanliness) with people who have a specific disease (Katz, in Alonzo and Reynolds, 1995:304), thus 'stacking' meanings and values onto a biological phenomenon like disease. But the process often happens in reverse, with existing negatively-defined groups being represented as disease carriers (for example, commercial sex workers and gay men). Disease stigmas draw heavily on existing negative definitions of the 'other' and other social representations. In dominant group representations, which usually gain greater currency in society, these definitions often identify and blame existing marginalised groups in society, following existing lines of inequality. This association is often given credence by the fact that existing social inequalities can affect the epidemiology of disease, making marginalised groups more vulnerable to disease and less able to find (private) treatment. HIV and AIDS stigmatisation relies heavily on existing prejudice and social stereotypes. The relationship between disease stigma and other forms of prejudice has been called multiple stigmatisation, double (or even triple) stigmatisation (Grossman, 1991; Hergovich, Ratky & Stollreiter, 2003: 37), following a trend in racism and gender

studies in which it is argued that different kinds of prejudice are added together. But disease stigmatisation operates in a slightly different way. Disease stigmatisation does link diseases with negative meanings, but often by suggesting that already-defined out groups are somehow responsible for the disease because of certain negatively-valued traits or behaviours, rather than representing all people with a particular disease in the same way. For example, some PLHIV are perceived as innocent victims (those who contracted HIV through blood transfusions or childbirth), while others are considered blameworthy because they contracted it through 'deviant' behaviour (sex that is considered immoral) that demonstrates their membership of already marginalised communities (such as commercial sex workers and gay men).

Forms of HIV and AIDS related stigma and discrimination

In some societies, laws, rules and policies can increase the stigmatisation of people living with HIV and AIDS. Such legislation may include compulsory screening and testing, as well as limitations on international travel and migration. In most cases, discriminatory practices such as the compulsory screening of 'risk groups', both furthers the stigmatisation of such groups as well as creating a false sense of security among individuals who are not considered at high-risk. Laws that insist on the compulsory notification of HIV and AIDS cases, and the restriction of a person's right to anonymity and confidentiality, as well as the right to movement of those infected, have been justified on the grounds that the disease forms a public health risk (Brown et al 2005: 71).

Perhaps as a response, numerous countries have now enacted legislation to protect the rights and freedoms of people living with HIV and AIDS and to safeguard them from discrimination. Much of this legislation has sought to ensure their right to employment, education, privacy and confidentiality, as well as the right to access information, treatment and support.

Governments and national authorities sometimes cover up and hide cases, or fail to maintain reliable reporting systems. Ignoring the existence of HIV and AIDS, neglecting to respond to the needs of those living with HIV infection, and failing to recognize growing epidemics in the belief that HIV and AIDS 'can never happen to us' are some of the most common forms of denial. These denials fuels AIDS stigma

by making those individuals who are infected appear abnormal and exceptional (Brierber, 2005: 86).

Stigma and discrimination can arise from community level responses to HIV and AIDS. The harassing of individuals suspected of being infected or of belonging to a particular group has been widely reported. It is often motivated by the need to blame and punish and in extreme circumstances can extend to acts of violence and murder. Attacks on men who are assumed gay have increased in many parts of the world, and HIV and AIDS related murders have been reported in countries as diverse as Brazil, Colombia, Ethiopia, India, South Africa and Thailand. In December 1998, Gugu Dhlamini was stoned and beaten to death by neighbours in her township near Durban, South Africa, after speaking out openly on World AIDS day about her HIV status.

Families

In the majority of developing countries, families are the primary caregivers to sick members. Families and households in Africa currently face significant adverse demographic, social, and economic changes resulting from the region's severe HIV epidemic. In a context of high HIV prevalence and incidence, many people experience HIV and AIDS illnesses and deaths in their own households, extended families and wider communities. Widespread HIV transmission between heterosexual partners and vertical transmission from mothers to children, men that affected households are likely to undergo multiple episodes of illnesses and deaths, often in quick succession. There is therefore clear evidence of the importance of the role that the family plays in providing support and care for people living with HIV and AIDS. However, not all family response is positive. Infected members of the family can find themselves stigmatised and discriminated against within the home. There is also mounting evidence that women and non-heterosexual family members are more likely to be badly treated than children and men. The excerpt below from two women illustrates this.

My mother-in-law has kept everything separate for me – my glass, my plate, they never discriminated like this with their son. They used to eat together with him. For me, it's 'don't do this' or 'don't touch that,' and even if I use a bucket to bathe, they yell 'wash it, wash it'. They really harass me. I wish nobody comes to be in my situation and I wish nobody did this to anybody. But what can I do? My parents and brother also do not want me back. (HIV-positive woman aged 23.)

Source: Avert.org <http://www.avert.org/aidsstigma.htm> 16.04.2003

“When I was in hospital, my father came once. Then he shouted that I had AIDS. Everyone could hear. He said: this is AIDS, she’s a victim. With my brother and his wife I wasn’t allowed to eat from the same plates, I got a plastic cup and plates and I had to sleep in the kitchen. I was not even allowed to play with the kids.” HIV-positive woman, Zimbabwe

Source: Avert.org <http://www.avert.org/aidsstigma.htm> 16.04.2003

Health Care

Many reports reveal the extent to which people are stigmatised and discriminated against by health care systems. Many studies reveal the reality of withheld treatment, non-attendance of hospital staff to PLHIV, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines. Also fuelling such responses are ignorance and lack of knowledge about HIV transmission.

There are many ways in which HIV-related stigma manifests in health care settings. A study in Tanzania documented a wide range of discriminatory and stigmatizing practices, and categorized them broadly into neglect, differential treatment, denial of care, testing and disclosing HIV status without consent, and verbal abuse/gossip. Similarly, a study in Ethiopia found that common forms of stigma in health facilities were designating PLHIV as HIV positive on charts or in wards, gossiping about PLHIV's status, verbally harassing PLHIV, avoiding and isolating HIV-positive PLHIV, and referring PLHIV for HIV testing without counselling Banteyerga H et al 2004.

A survey conducted in 2002 among some 1,000 physicians, nurses and midwives in four Nigerian states, came up with disturbing findings. One in 10 doctors and nurses admitted having refused to care for an HIV and AIDS patient or had denied PLHIV admission to a hospital. Almost 40 percent thought a person's appearance betrayed his or her HIV-positive status, and 20 percent felt that people living with HIV and AIDS had behaved immorally and deserved their fate. One factor fuelling stigma among doctors and nurses is the fear of exposure to HIV as a result of lack of protective equipment. Also at play, it appears, was the frustration for not having medicines for treating PLHIV, who therefore were seen as ‘doomed’ to die (Obasike, 2002:34).

Lack of confidentiality has been repeatedly mentioned as a particular problem in health care settings. Many people living with HIV and AIDS do not get to choose how, when and to whom to disclose their HIV status. When surveyed recently, 29% of persons living with HIV and AIDS in India, 38% in Indonesia, and over 40% in Thailand said their HIV-positive status had been revealed to someone else without their consent. Huge differences in practice exist between countries and between health care facilities within countries. In some hospitals, signs have been placed near people living with HIV and AIDS with words such as 'HIV-positive' and 'AIDS' written on them <http://www.avert.org/aidsstigma.htm> 16.04.2003. Stigma and discrimination in the health care setting and elsewhere contribute to keeping people, including health providers, from adopting HIV preventive behaviours and accessing needed care and treatment. Fear of being identified as someone infected with HIV increases the likelihood that people will avoid testing for HIV, disclosing their HIV status to health care providers and family members, or seeking treatment and care, thus compromising their health and wellbeing (Mahendra V.S et al 2007).

The way forward

HIV-related stigma and discrimination remains an enormous barrier to effectively fighting the HIV and AIDS epidemic. Fear of discrimination often prevents people from seeking treatment for AIDS or from admitting their HIV status publicly. People with or suspected of having HIV may be turned away from healthcare services, employment, or refused entry into a foreign country. In some cases, they may be evicted from home by their families and rejected by their friends and colleagues. The stigma attached to HIV and AIDS can even extend into the next generation, placing an emotional burden on those left behind.

HIV and AIDS threatens the welfare and well being of people throughout the world. At the end of the year 2007, 33 million people were living with HIV or AIDS and during the same year 2 million died from AIDS-related illness <http://www.avert.com> (20.10.09). Combating the stigma and discrimination against people who are affected by HIV and AIDS is as important as developing the medical cures in the process of preventing and controlling the global epidemic.

Progress can be made in overcoming stigma and discrimination. People's attitudes to AIDS can be changed. A certain amount can be achieved through the legal process. In some countries people who are living with HIV or AIDS lack knowledge of their rights in society. They need to be educated, so they are able to challenge the discrimination, stigma and denial that they meet in society. Institutional and other monitoring mechanisms can enforce the rights of people living with HIV or AIDS and provide powerful means of mitigating the worst effects of discrimination and stigma.

However, no policy or law can alone combat HIV and AIDS related discrimination. The fear and prejudice that lies at the core of the HIV and AIDS discrimination needs to be tackled at the family, community, institutional and national levels. A more enabling environment needs to be created to increase the visibility of people with HIV and AIDS as a 'normal' part of any society. In the future, the task is to confront the fear based messages and biased social attitudes, in order to reduce the discrimination and stigma of people who are living with HIV or AIDS.

2.27 HIV and AIDS Counseling

Counselling

Counselling is defined as a confidential dialogue between a client/patient and a care provider aimed at enabling the client to cope with stress and take personal decisions such as those related to HIV and AIDS. Counselling enables a client/patient to open up and share his/her emotional fears, guilt, and anxiety as well as more practical issues with regard to the future, survival and planning for one's children. Good counselling can only be done by those who are personally committed to care and may involve nurses, social workers, doctors, religious leaders or others. Post-test and follow up counselling eases the provision of care and facilitates disclosure to a family member who may be willing to provide home care. One post-test counselling session is usually not enough. A person may need on going support or the option to return for more sessions if they wish. Counselling after a positive test results in breaking the bad news to the individual, assessing, understanding and emotional acceptance of the result, and dealing with any immediate reactions. However post-test counselling is not complete until the client has made plans to meet the challenges of living with the infection.

According to the World Health Organization (WHO 2007), they define HIV counseling as a confidential dialogue between a patient and the counselor or care provider aimed at enabling the patient to cope with the stress and to take personal decisions relating to HIV infection and AIDS morbidity and mortality http://www.searo.who.int/LinkFiles/Training_Materials_voluntary-module2-.pdf

23.09.09. Counseling in HIV and AIDS care is an interaction of information exchange, skill acquisition and emotional support between the counselor, the person infected with HIV and others significant to the client who include family members, friends, health practitioners, employers and people who give spiritual support. The interaction is directed at meeting the physical, mental, and social health and functioning: to provide continuous support and to prevent HIV transmission to others. Counseling not only assists people who already have the infection to cope with the consequent problems, but also evaluates the risks of HIV transmission and facilitates behavior to prevent further infection. Counseling in HIV and AIDS means giving information, facilitating risk reduction behavior, and providing unconditional emotional support to the people affected. AIDS counseling is different from other forms of care. The disease is not only a health problem for the family and society; it is also associated with intense and progressive human suffering which arouses diverse emotional reactions. Such reactions include fear, denial, loss, grief, anxiety, anger, rejection, isolation, annoyance, blame apportioning, pity, self-condemnation, depression, and suicidal thoughts (WHO 2007). Managing the disease involves personal issues and often requires talking about things that are dreaded and aspects of life ordinarily considered very private. These are concerns about whether AIDS will develop and whether family or friends will reject the person infected. There will be doubts about their willingness to give support and about the availability and usefulness of treatment and the course of the illness. The clients might also be fearful of the social attitudes that question their self worth and may bring scorn on the family. HIV also brings anxiety about possible family conflicts and problems concerning work and finances as the disease progresses. There may also be problems with friends, problems about meeting basic life needs, problems derived from sexuality and sexual relationships, changes in the body image and anxiety about death and dying.

In the face of all these, counseling is a very important activity to anyone who has been diagnosed as HIV positive. How a person copes with a terminal illness such as this

one is very much largely dependant on the amount of counseling received by a client. Counseling has helped several PLHIV who have been diagnosed as HIV positive cope with their illness and look at life with a very positive image (WHO 2006). The factors that make HIV infection and AIDS unique make necessary specialized counseling which accordingly should provide personalized information and give social and psychological support focused on strengthening the client's sense of responsibility. HIV positive people need this information to help them accept and develop a completely new lifestyle. In the end, HIV and AIDS counseling not only helps the client, it also protects the other members of the family and community as clients are shown their role in preventing infection and in contributing to the general control of the disease.

Support groups and networks

In many countries around the world, people with HIV, and sometimes their relatives have formed support groups. In the West, and in some developing countries, these groups are a powerful force for the rights of people living with HIV, challenging discrimination, advocating for access to treatment, promoting counseling and support services and seeking legal protection for human rights. Some of these support groups are mainly of those people living with HIV and AIDS. At a personal level, PLHIV can be especially influential policy makers, advocates, peer educators, and service providers. In the continued environment of stigma and fear surrounding AIDS, the opportunity to meet people who openly discuss their HIV status, what it means and how they are coping is a powerful liberating experience. Support groups help to highlight to those infected and those affected on how others are coping with the epidemic in their midst (Howard 2003:87)

In Uganda, a support group called The AIDS Support Organization (TASO) was formed in 1987. TASO has been instrumental in the formation of support groups, calling for access to treatment, de-stigmatization, of HIV and AIDS by encouraging people to openly talk about it <http://www.tasouganda.org> 16.04.09.

CHAPTER 3

STUDY AREA AND METHODS

3.1 Area of investigation

The area of study was Mutambi ward in Zvishavane District, Midlands Province in Zimbabwe. Zimbabwe has 60 administrative districts and this study looked at Mutambi ward in Zvishavane. Zvishavane town, the district capital, is a small mining town in Zimbabwe. According to statistics released by the Ministry of Health in 2003 to 2006, high rates of HIV prevalence have been reported here, with 75 percent of all hospital admissions and fifty nine percent of the deaths recorded in 2004, 2005 and 2006 were reportedly due to HIV and AIDS illnesses.

Mutambi Ward is located 45 km south east of Zvishavane town, and lies between the 30⁰ and 31⁰ longitude and 20⁰ and 21⁰ latitudes. Mutambi Ward is part of rural Zvishavane, it being part of what are commonly known in Zimbabwe as “communal lands” or state land held in trust by peasant or subsistence farmers. The 4, 000 people in Mutambi Ward follow either Christianity or traditionalism. The ward has a total of five headmen and these are Chishapira, Mwedzi, Mutonga, Msibandi and Nhedzi. The social affairs of Mutambi are the responsibility of both traditional and political leadership. One of the study sites was Zungwi Vlei, a crop production project with a total of 45 farmers. Zungwi Vlei is a broad ridge and broad furrow project commonly known as a wetland. This is a system where the ridges trap water and feeds it to the furrows. Crops like rice are then grown on the ridges and maize and groundnuts in the furrows. This irrigation system in a good rainy season retains water and moisture stored allows cultivation throughout the year.

Mutambi Ward occupies the upper latitude zone of Zvishavane with vast expanses of land being used for agricultural activities such as the growing of maize, groundnuts, and cowpeas in the rainy season, and gardening in the other seasons. Community members also engage in livestock rearing and have cattle, goats, poultry and sheep. Mutambi Ward falls in the Natural Farming Region 3, which is semi-extensive farming because of low to medium rainfall, and has several wetlands and undulating hills. Zvishavane is low lying, hot, and receives seasonal rainfall. Although sale of

agricultural produce is the main source of income in Mutambi Ward, community members also engage in other income generating activities to supplement their income. Some of these include gold panning, cross border trade, knitting, sewing, and sale of livestock.

Furthermore, the community has a well-developed road network, being situated close to the highway and with gravel roads that connect one village to the others in the community. The ward has a total of three clinics that rarely had medication, and nurse-aides managed these clinics. Given this situation, community members have to travel a distance of 50 km to go to the District Hospital, with a large proportion of the community resorting to other health-seeking behaviours such as visits to traditional healers, self medication at home because of their perceived advantages over medical institutions.

The geographical area covered by the study is illustrated in figure 2 below.

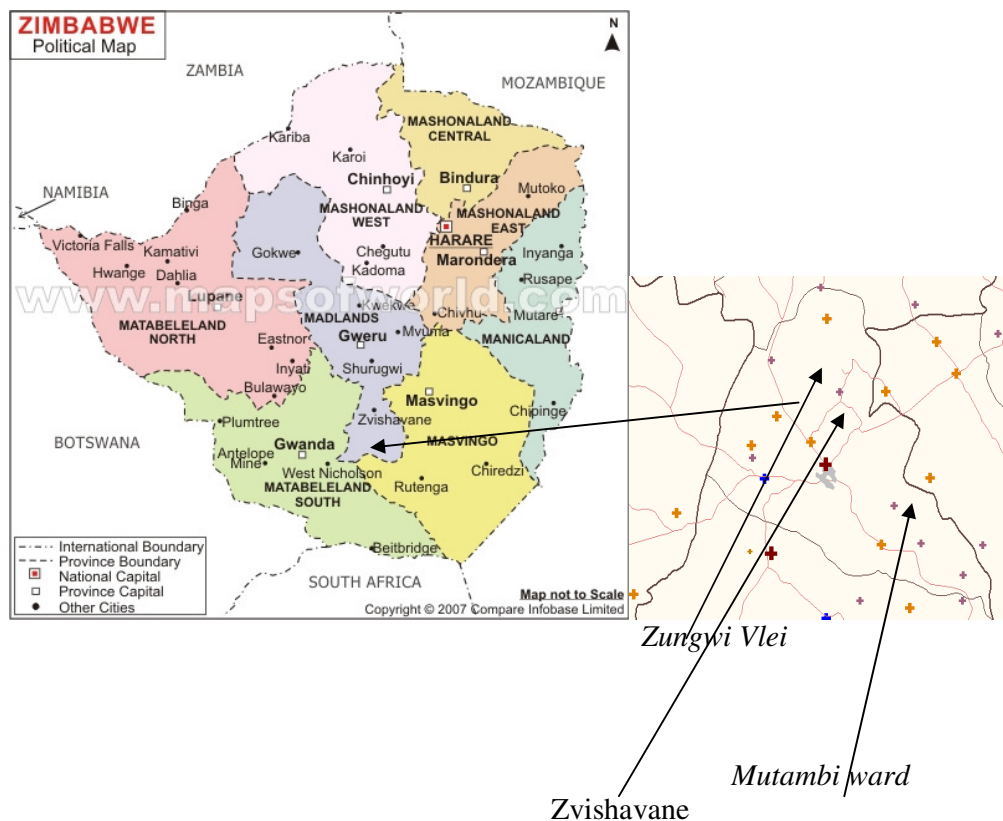


Figure 2: Map of Zimbabwe and Zvishavane indicating study area

Study period

This study was conducted between May 2004 and October 2006. Field visits were made every month with the exception of December. Data collection was an on-going process throughout the year and this was possible because the project employed Local Research Assistants who were members of Mutambi Ward.

3.2 Study population and sampling

The study participants were drawn from Mutambi Ward. The study was conducted in all the five villages of the ward (Chishapira, Mwedzi, Mutonga, Msibandi and Nhedzi). In total, 450 people out of a total population of 4000 people participated in the study. Focus group discussion participants were based on those who responded to the invitation to come and participate. Scheduled interviews were also done with key informants who were seen by the study to be essential and would be able to talk on issues related to the study. Questionnaires were administered on a subset of the population, based more on accessibility of respondents.

3.3 Description of study participants

The study participants were in the range of 17 to 84 years. The household size ranged from 4 to 15 people. The community had a mixture of Traditionalists and Christians with 38% admitting to practising both. All people included in the study were residents of Mutambi Ward.

3.4 Research design

This study was a descriptive and analytic cross sectional study. A cross-sectional study is a descriptive study in which disease exposure and outcome status is measured simultaneously in a selected population.

The study therefore adopted a qualitative research design in the form of a case study. As pointed out by Yin (1979, 1998) a case study is the appropriate research design for studying social phenomena in a real life context. In this case, this study examined the dynamics of HIV and AIDS within the real life context of a community, and the responses of individuals, families, households, and the community as a whole, bringing out the real life challenges they faced. The qualitative design was more useful because of its emphasis on quality and validity. It looks for questions and

answers; it gains or captures insiders' perspectives; it is open to explore the unexpected; it focuses on signs and symbols that decode the reality seen by the target population, examining both verbal and non-verbal behavior in order to understand the views, attitudes and perspectives of the respondents; it is interactive and offers opportunities to probe, generating a hypothesis and is concerned with why things are the way they are and with what meaning they have for the people concerned.

This study focused on HIV and AIDS which is typically a complex epidemic in a community, its economy, social life, cultural practices and political organization. It is known that HIV and AIDS have shaped behaviours and decisions at the individual, family or household and community level. Such behaviours and decisions do not always follow common logic or economic rationality because they are the outcome of a very complex set of many variables. Given this reality, it was therefore dangerous to make generalisations. The key challenge rather was to gain deeper understanding of the underlying motivations for these behaviours and decisions both individual and collective rather than to arrive at mere generalisations.

3.5 Data collection methods

This research employed a compendium of approaches to data collection. Qualitative and quantitative data collection tools were used as a result. First and foremost, participatory field research work to obtain primary data for the baseline study was conducted as a community diagnosis survey. The aim being at promoting action and community level change, and ensure that all perspectives and insights of all stakeholders, beneficiaries as well as project implementers are taken into consideration. The other reason was to investigate whether HIV and AIDS were perceived as health challenges by the community. Participatory methods of collecting data were used to facilitate learning about local-level conditions and people's perspectives and their priorities during project appraisal. Data collection was an ongoing process over the two years and this was made possible by the presence of Local Research Assistants in Mutambi Ward. The following data collection tools were used;

Data collection tools

3.5.1 Focus group discussions (FGDs)

These are a tool for collecting data from discussions held in groups, and were useful for collecting in-depth qualitative information about groups' perceptions, attitudes and experiences on a defined topic (Babbie, 1997:34). These were conducted with community members on several issues related to the study. Focus group discussions were particularly useful because of the following reasons: they gave insight into not just what participants thought, but why they thought it. They also revealed consensus and diversity of participants' needs, experiences, preferences and assumptions; they allowed group interaction such that participants were able to build on each other's ideas and comments to provide an in-depth view not attainable from individual questioning; they also allowed probing of all issues and further clarification on issues raised by participants and exploring different views could be possible as well; and unexpected comments, new perspectives and new ideas could also be explored easily.

In total, 28 FGDs were held. These were held with different groups of people and in different villages of Mutambi ward. 8 FGDs were held with men only, 10 with females only and another 10 with a mixture of both men and women. The reason for separating men and women in some sessions is because females were overpowered by males during discussions of sensitive and intimate issues. In a few instances, women were grouped up with their husbands or their fathers and were reluctant to share their views. Firstly, 6 FGDs to rank diseases during the community diagnosis exercise were held. These were held in five different villages with two being held in one village. 2 more rankings in a focus group discussion setting were held a year after to see if there was any change in the diseases giving the community great challenges. 4 more FGDs were held to explore impacts of HIV and AIDS on one study group which is the Zungwi Vlei and the resultant strategies adopted by the community to cope were also explored in these FGDs. A total of 6 separate FGDs were held in different villages exploring the issues of impact of HIV and AIDS at the community level, responses by different households and coping strategies at the community level. These FGDs also explored issues raised in questionnaire responses. FGDs were also held with home-based care facilitators because these helped to bring insight into how households were coping with the impacts of HIV and AIDS. A total of 4 FGDs were held with these facilitators. Another set of 6 FGDs was held in different villages to explore issues of

disclosure, stigma and discrimination.

3.5.2 Interviews

Semi-structured interviews and in-depth interviews were used during the study because of their many advantages over alternative methods. Semi-structured interviews were guided interviews based on pre-determined topics and were very flexible and allowed the researcher to adjust to the demands of the present context in an effort to collect detailed relevant data (Hakim 1994). They allowed probing and rephrasing of questions according to the different responses of interviewees. Semi-structured interviews were also particularly useful especially in order to get deeper insights into people's experiences with HIV and AIDS, their opinions, aspirations, attitudes and feelings. In-depth interviews, on the other hand, allowed both the interviewer and the interviewee to explore the meaning of the questions and answers involved. Formal interviews were not completely ruled out. They came in handy when there was need to elicit for more elaborate information. Interviews were particularly important because they could provide information that could not be obtained either through observation or through questionnaires.

Individual interviews were held with the different participants of the study and individualism allowed issues that could not be brought up in a group setting to be brought up, largely because of their confidential or controversial nature. They also brought out more insight and in-depth information specific to each unit. A total of 36 interviews were held with different professional and key informants in the community. 15 were structured and 21 were semi structured interviews. Key informant interviews were held with people believed to have expert knowledge on particular issues. The social process during key informant interviews was different from that with professional key informants because the former was governed by a variety of cultural conventions and expectations. The whole point of not fixing an interview structure with predetermined questions was to permit freedom to introduce materials and questions previously unanticipated, even though a prepared guideline was present. Key informant interviews were carried out with the following people: community leaders, environmental health workers, nurse aides, spiritual healers, home-based care facilitators, family care givers, and church leaders. Four were held with community traditional leaders and political leaders, 12 with home based care

facilitators, two with traditional healers, one with the extension health worker and one with the clinic nurse. On the other hand, a total of 20 in-depth interviews were held. Ten in-depth interviews were held with family care givers and 10 were also held with PLHIV.

3.5.3 Review of records

Records were reviewed by the study in the process of data collection. These records included a variety of archival material (from the home-based care programme) and running documents (also from the home-based care programme). Indirectly, records were used by key informants during interviews for verification on responses. This was evident in cases such as interviews with the Chief and Councilor who needed to explain the different roles being played by the different organizations that were helping the community.

3.5.4 Structured questionnaires

Structured questionnaires were made up of formal questions framed and written down for the respondents to provide answers to. The questionnaire as a method of data collection was an efficient way to collect statistically quantifiable information (Babbie 1997). The exact wording and sequence of questions were determined in advance, respondents were asked the same questions in the same order. Questions were worded in a completely open-ended format. Respondents answered the same questions thus increasing comparability of responses. The questionnaire was also very useful in bringing out issues that were to be discussed in a focus group discussion setting. It was an efficient method in the sense that many respondents could be reached within a short space of time. Six sets of questionnaires were administered to the study participants. The first set a combined questionnaire of different disciplines was administered to collect baseline data. Two sets of structured questionnaires was administered on HIV and AIDS awareness, impact on livelihood, impact on Vlei activities, treatment measures sought and coping strategies adopted. One set was on Vlei households and the other was on non-Vlei households. A total of 62 questionnaires were administered. A further 2 sets of structured questionnaires were administered on the Vlei households and non-Vlei households on impact of HIV and AIDS and coping strategies adopted. A total of 33 Vlei members responded to the questionnaire. The last set of questionnaires was administered on home-based care

facilitators.

3.5.5 Narratives

These are defined as stories or an interpretation of aspect of the world that is historically and culturally grounded and shaped by the human person based on one's experiences. Ten narratives were held with family care givers and ten PLHIV. In everyday communication, humans often tell narratives as a means of sense making, explaining situations, experiences and for people to better understand events and circumstances.

3.5.6 Zungwi Vlei diary

A Zungwi Vlei diary was also used for data collection. The Vlei diary recorded the number of people who attend to Vlei activities every Friday of the year. It was mainly recorded on Friday because this is the day that was set aside by the Vlei project members for working on the Vlei. The diary was however recorded on other days besides Fridays when project members had decided to attend to some work. The Vlei diary recorded the date, the number and sex of project members present for work, the amount of time spent working, the activities covered and other interesting and relevant observations.

3.5.7 Death and burial register

Another tool to complement the Vlei diary made use of was a death and burial register. The death and burial register was recorded to show how many absenteeism's were a direct result of deaths and burials. It was collected from October 2005 to March 2006. The death register collected data relating to the date of death, burial date, age of the deceased, suspected cause of death and whether the dead was a member ordinarily resident in the community or whether he or she was brought from town or elsewhere.

3.5.8 Participant observations

Participant observations were also used as a data collection tool and a particular checklist was drafted for this purpose. Both direct and indirect observations were made. Participant observations were useful because they served a formulated research purpose, were planned deliberately, were recorded systematically and were useful in

checks and controls on validity and reliability. Observations allowed the selection of the range of things to be observed on the basis of the nature, scope and objectives, were purposive and captured the natural social context in which a person's behavior occurred. Lastly, they grasped the significant events and occurrence that affect social relationships of the participants.

3.6 Validity and reliability of research results

Accuracy and precision of research results was made possible by validation of research results by the researcher. Findings were summarized to the participants normally after focus group discussions and some of these results included even those that came out from instruments such as questionnaires, interviews, and observations. Triangulation was also made use of, in cases where two or more instruments were used to explore the same variables of interest to the study. Participant and non-participant observations were also made in cases where the researcher could verify responses from study participants, for example claims that people do not work on burial days, roles and responsibilities of women, and land use activities. Lastly, a community feedback meeting was held where research results were presented to Mutambi Ward community so that they could authenticate the findings.

Reliability

Reliability concerns the degree to which the values obtained from repeated measurements of the same persons – under similar conditions – yield the same result. Reliability of results was enhanced by the large sample size that was made use of, through the use of a standardized sampling frame, and through the use of standardized and properly structured questions.

Validity

Two types of validity were considered, namely, internal and external validity. Internal validity refers to the lack of bias among the groups compared within a study. The study findings are internally valid because a large sample size was used, standardized instruments were used and analysis of data collected from the study revealed coherence in views brought about by respondents.

External validity concerns the generalizability of a study's results beyond the

particular groups participating in the study. Generalizability primarily concerns how well the study population represents other populations. The findings of this study can however not be generalized to other populations. This is because this was a case study and findings largely related to how this particular community was responding to the impacts of HIV and AIDS. These responses were defined by inherent characteristics of the community that may not be similar in any way to any other community.

3.7 Data entry and data analysis

All questionnaires administered were cleaned, coded and entered into SPSS 9.0 after each fieldtrip. A set of four questionnaire sets were administered in Mutambi Ward and they were entered into SPSS 9.0.

Data analysis for questionnaire responses was done in SPSS 9.0 basing on the different coded variables of interest to the study. Data from focus group discussions and in depth interviews was coded according to different themes and variables the study was measuring.

3.8 *Limitations of the study*

HIV and AIDS is a sensitive subject in most parts of the world, especially in rural areas where villagers do not feel comfortable discussing it with researchers. Talking about HIV and AIDS was seen by some villagers as admitting to either being HIV positive or having a family member(s) who is/are affected. It was the general belief that one has something to talk about on HIV and AIDS only when they had a direct experience with it. This was the general feeling among community members at the beginning of the study. Very few respondents opened on issues concerning HIV and AIDS. It was only those who were in the home-based care programme (facilitators, PLHIV or family care givers) who had no reservations when discussing issues concerning HIV and AIDS. HIV and AIDS were largely a sensitive topic to discuss. This mentality, however, changed during the course of the study. The long period of the study helped in creating a rapport with community members, resulting in them opening up more and more.

Also, due to the sensitivity of HIV and AIDS issues, discussions during FGD's with both males and females resulted in males' domination. Dominance was also noted

during FGD's that were attended by a figure of authority in the community. In the end, FGD's with males only and females only were arranged when sensitive topics were discussed. Authority figures in the community were also given their own forum during interviews to avoid them overpowering their subjects.

3.9 Theoretical and conceptual framework of the study

This study explored the complex dynamics of HIV and AIDS in a community whose whole livelihood is under threat and whose whole economy is already fragile. The focus taken by the study is on the mechanisms that the community on has devised on its own in order to cope with the challenges of HIV and AIDS. It also looks at the external support provided for the community to cope better, and the extent to which both have been successful.

This study used the narrative inquiry theory. This is a process of gathering information for the purpose of research through story telling and narrations from different experiences. The researcher then writes a narrative of the experience. Connelly and Clandinin (1990:29) note that "humans are story telling organisms who individually and collectively lead storied lives". Thus the study of narratives is the study of the ways humans experience in the world. In other words people's lives consist of stories.

Field notes, in depth and structured interviews, letters, autobiographies and orally told stories are all methods of narrative inquiry. A study on community coping strategies to the epidemic involved narrative inquiry on how their livelihoods have been changed as a result of HIV and AIDS and how they are overcoming, responding to, or coping with their situations.

The overall design of the study was guided by a clear framework that assumed the presence of a certain relationship among HIV and AIDS related factors. The impacts of HIV and AIDS are more devastating in small rural communities because of their fragile economies (Rugalema, 2003:534). These impacts are ultimately felt at all levels, but it is at the household level that the impacts are managed on a day-to-day basis. Since the management of PLHIV requires human resources (people with the right skills and with the time), material resources that facilitate home-based care (such

as gloves, food, bedding, soap and detergents), financial resources (e.g. for medication, transport, etc), and the psychological will to act (motivation to look after the sick, and provision of emotional support), these households' ability to cope with the impacts were largely determined by their overall resource endowment.

Households, however, are part of the wider community, and their choice of action (or non-action) is to some extent influenced by the broader community framework. This framework consists of the community's livelihood (the economy and resources available within the community), its cultural values (what they feel is permissible or forbidden), social practices adopted by the community's members, the emotional or psychological disposition of the community's members (stress levels, provision of empathy, cohesion and support), and the patterns of power that govern members actions and behavior.

The extent to which households cope or fail to cope with the impacts of HIV and AIDS, is a result of the degree of match between the demands brought about by HIV and AIDS on the one hand, and the availability of resources required by the household to meet these demands on the other. Similarly, the choice of coping strategies is also largely determined by the dictates of other factors within the household's broader environment, and the household's perception of the efficacy of one or more strategies over another or others. Figure 3 below illustrates this framework.

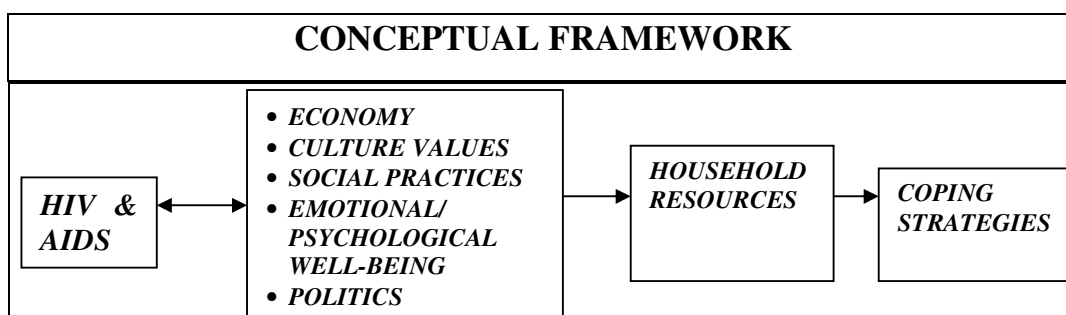


Figure 3: Coping with Impacts of HIV and AIDS at Household level: Conceptual Framework

3.10 Household coping with HIV and AIDS

HIV and AIDS come in three stages. These are the asymptomatic stage, symptomatic stage and the end of life stage. For a household to cope, it must prepare itself for these

stages. The stages have different challenges as these challenges grow increasingly as the disease progresses to become AIDS. Below is Figure 4 that shows how a household can cope.

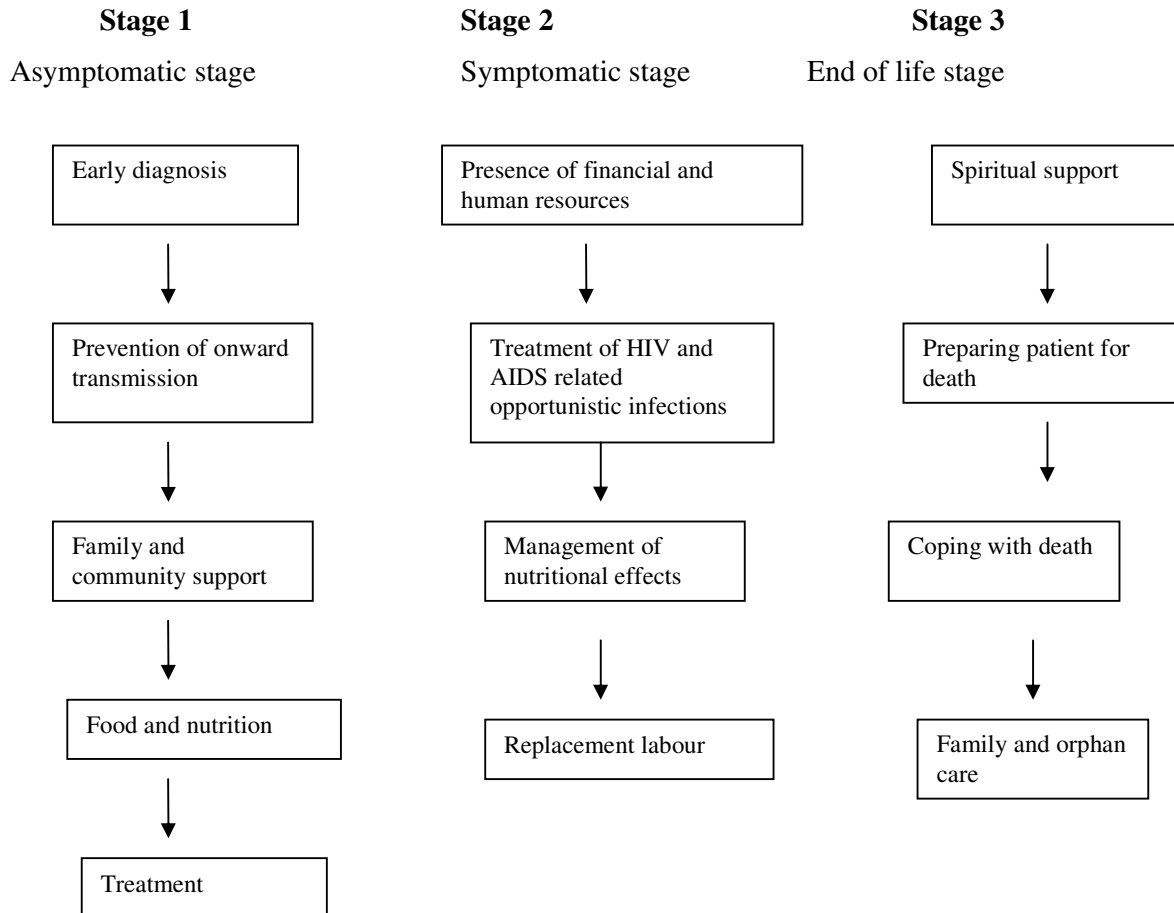


Figure 4: Coping with challenges at different stages of HIV and AIDS

3.11 Conclusion

The theoretical and conceptual framework presented in this chapter serves as the basis not only for the identification and examination of the key variables for this study and how they are inter-related, but also as the basis for the analysis of data gathered as well as the interpretation of the data. By presenting this framework, it is easier to capture the meaning and the key messages conveyed by participants in the research, with a particular focus on how they coped or failed to cope with the challenges of HIV and AIDS.

CHAPTER 4

PRESENTATION AND INTERPRETATION OF DATA

4.1 Introduction

The aim of this chapter is two-fold. First, the researcher makes a presentation of the data collected using the various tools. The presentation is done in the form of tables and, in some cases, verbatim transcriptions of respondents' views and answers to questions. Second, the researcher analyses the data in an effort to extract meaning out of it. In this analysis, the researcher keeps in perspective the questions originally presented in Chapter One, the aim being to provide answers to the questions posed.

The findings and analysis are also related to the other body of knowledge presented in the review of literature in order to find out whether the data corroborates what is already known as well as new insights it reveals on the issues in question.

4.2 Community Diagnosis

Initially, a community diagnosis survey was carried out before the onset of the study. This exercise was carried out to get an overview of the community and to have a better understanding on the running of the community. It was during this exercise that HIV and AIDS were raised as the greatest health challenge the community was facing. The disease ranking exercise was as follows

Table 4: Ranking of diseases by community in order of perceived importance

Disease	Reported Occurrence
1. HIV and AIDS	Not Seasonal
2. Tuberculosis	Throughout the year
3. Malaria	Rain Season
4. Influenza	Throughout the year
5. Sexually transmitted infections	Throughout the year
6. Heartburn and diarrhoea & cholera	Dry and hot season
7. Headache	Dry and hot season
8. Problematic feet	Throughout the year
9. Kwashiorkor	Dry and hot season

4.3 Baseline survey

A baseline survey was then carried out to ascertain the extent to which HIV and AIDS had impacted on the community and the coping strategies they had adopted as a result. The baseline survey was held in two different sections of the community. Table 5 presented below highlights the perceived impacts of HIV and AIDS by community activities.

Table 5: Perceived impacts of HIV and AIDS on community activities

Activity Impacted on	Percentage of Responses
Productive activities and household activities	96% of the responses contend that HIV and AIDS have adversely affected productive activities.
Vlei Activities	94% of the responses reiterated that HIV and AIDS had affected Vlei activities
Community activities	98% of the responses contend that HIV and AIDS have negatively affected the community
Death rate	72% of the responses indicated that death rates had increased
Life expectancy	96.4% of the responses said life expectancy had dropped to 40 years.

4.4 Coping Strategies

From the responses provided by members of the community, the perceived strategies for coping with the diseases were tabulated, and these have been presented in Table 6 below.

Table 6: Perceived coping strategies in the community

Coping Strategies	Percentage (%)
Home-based care programme	48
Counseling	16
Faith based healing	10
Eating a balanced diet for those already infected with the virus	8
Initiatives from NGOs, churches and other stakeholders	8
Positive change on sexual behavior	6
Information dissemination	4

4.5 Ranking of diseases by prevalence

Members of the Zungwi Vlei community were requested to identify the main diseases to rank them in the order of the seriousness of their impacts. They were also requested to indicate whether they mostly affected males, females or both sexes. Their responses have been presented in Table 7 below.

Table 7: Occurrence of disease by most affected sex

Disease	Occurrence	Sex
1. HIV and AIDS	All throughout the year	Male and female
2. TB	All throughout the year	Male and female
3. Diarrhoea	All throughout the year	Male and female
4. Headache	In the hot season (October to March)	Male and female
5. Sexually transmitted infections (STIs)	In the hot season (October to March)	Male and female
6. Back problems	In the winter and rainy season	Female
7. Uterus problems	In the winter season (May to August)	Female
8. Malaria	In the rainy season (December to March)	Male and female

From the responses presented in Table 7 above, it is clear that HIV and AIDS have been indicated as the greatest health challenges the community was facing. Table 7 shows disease with the Zungwi Vlei community ranking in 2006. This was also highlighted in a focus group discussion that was a follow up of the disease ranking exercises done earlier.

4.6 Historical Background

A focus group discussion was subsequently held to establish the historical background of the emergence of HIV and AIDS in the community.

According to participants in a focus group discussion, from 1998 there was a lot of illness amongst community members. These illnesses resulted in increase in the number of deaths in the community. According to 78% of respondents from a questionnaire survey, this was largely due to the emergence of HIV and AIDS in the community. Participants said, *‘Those who fall sick do not recover. Some are ill for a long time. Usually it’s on and off. Then it gets to a point where the person cannot do*

any work. They then become bedridden and eventually they just die'. The description provided by the community members fits perfectly with the general cycle of HIV and AIDS.

Illness

Responses by participants in a focus group discussion revealed the perceptions of participants on how prevalent the pandemic had become in the community. HIV and AIDS, according to them, had been prevalent in the community because the government made a mistake of placing condoms in hospitals for people to just take at any time irrespective of age. This, according to participants, resulted in the young having access to condoms. As pointed by one participant, young people thereafter gained more access to condoms than the older members of the community. One participant confirmed this when he said, *'We, fathers, do not have condoms and we have never used them before'*.

More than 75 percent of respondents thought the introduction of condoms in the community was premature. People did not even know that condoms are not 100 percent safe. They thought they could not get the virus at all if they used the condoms. The young were also not educated enough to know the proper use of condoms. Those who wanted to exercise self discipline when condoms were introduced thought they could also try them out because they thought they would be safe and would be protected. Condoms were said to have tempted or encouraged people to indulge in sexual activities.

According to participants, long back, it was very rare for young people to die. It was the old who ordinarily died. But now it was the young that were dying, leaving the old behind. The young even gave the old the burden of looking after them first before they died. The young, according to the older participants in the FGD, had completely lost all the values that their forefathers instilled in them, and condoms were encouraging them to be promiscuous.

Furthermore, participants went on to say that traditional laws and culture were being ignored, this being a result of modernisation and Christianity. People always said they were Christians and this was especially true amongst the young children who did not

uphold tradition anymore following the rise community members who claimed to be Christians. However, claims of Christianity were an excuse to avoid upholding traditional laws. Participants went on to say the emergence of HIV and AIDS had also resulted in an influx of donors in the community. These have been helping the community in different ways. Most of them helped with food relief and preference was given to widows and households with orphans. Others helped with home-based care. Donors have also been helping with seed for agricultural activities and they gave preference to households with orphans, child-headed households or households with widows.

Source of infection

According to 68 percent of people in the community, HIV and AIDS came from the urban areas and quickly spread into the community. They thought HIV and AIDS was spread by those with their spouses who work in town who came regularly. The other 42 percent said the disease started off in the community with some saying it was spread by cross border traders, or those who migrated into the area for purposes of employment.

4.7 Impact of HIV and AIDS on upland farms

Participants were asked to indicate the major impacts HIV and AIDS had had on the community, and their responses have been presented in the table below. Please note that the percentages indicate the proportion of the respondents highlighting each of the impacts presented in the column on the left.

Table 8: Impact of HIV and AIDS on upland farms

Impact of HIV and AIDS	Percentage (%)
Increased absenteeism to productive activities (average of 16 people in attendance) Loss or reduction of labour	40
Enormous productive time spent on care related roles	36
Resources of agricultural inputs diverted to patient care	28
Loss or reduction of labour	24
Reduction in work rate due to increase in care related roles	12

A questionnaire was also administered to 86 non Vlei members. 72 percent of respondents mentioned that the impacts of HIV and AIDS-related activities had led to the neglect of agricultural activities. This neglect was mainly caused by the care-giving role, the search for health care services at the expense of productive time, loss of human resources (patient and the care giver), reproductive roles related to HIV and AIDS (these include fetching water for bathing PLHIV particularly those with diarrhoea or rashes, washing the PLHIV's linen and clothes, cooking for the patient, feeding the patient, taking the patient out of the house for some fresh air and so on). Bearing in mind the prolonged duration of the illnesses related to HIV and AIDS, these impacts are devastating. The other thing that makes situations of HIV and AIDS more complex is the heterosexual transmission of the disease. This results in HIV and AIDS normally striking more than once in the household. From those interviewed, 56 percent admitted to having more than one suspected HIV and AIDS patient at their household.

Food security

HIV and AIDS impacts on Mutambi Ward have added significantly to the problems of food security and have severely affected agricultural output. Agricultural production heavily relies on labour, yet available labour has been reduced in more than 60 percent of households. The impact has further been worsened by high mortality and morbidity, with an average of eight people dying in the community on a monthly basis. In 58 percent of households, HIV and AIDS impacts caused severe labour and economic constraints that disrupted agricultural activities, aggravated food insecurity, resulting in negative rural development. A few notable responses from respondents help to highlight this;

'Atisisina nguva yekusakura nekuti tinenge tichichengeta varwere. Mazuva murwere paanotomboita senane tinotombo jovha asi azvinyanyo kubatsira'. In English, we have limited time for cultivating because we have to look after the sick. However, there are a few days when the ill can be better and those days we try to cover up all the lost work but this isn't sustainable. (A married woman looking after a sick husband)

‘Chirwere ichi chero isu tisina vanorwara chinongoti bata. Anditi ndizuro chaiye patakabva kumariro pamusoro apo. Vhiki yapera taivako zvakare. Sesu madzimai echechi, zvinonyanyo tibata nekuti tinenge tichida kugarisana nevamwe zvakanaka’. In English, With HIV or AIDS even those without ill family members are affected. It’s only yesterday when we came from a funeral, and last week we were there as well. For us Christians, we have to show kindness and attend to all funerals as part of our Christian living. (A middle aged woman)

‘Kunesu anababa zviri nani nekuti anamai ndivo vanonyanyo tichengetera varwere. Asi kana urwere huri pamba pako, aungambozoendi kumunda zuva nezuva wakafara, unowana rimwe zuva raunorambidzwa neurwere kubva pamusha, haungambono shand zvakanaka kumunda kwacho’. In English, the caring role is mostly a female one, so for us men, we have some extra time to attend to our farms. However the presence of a sick person at household level changes things as one cannot go to the farm when the health of the sick family member deteriorates. Even if you go, your mind won’t be settled so you won’t do much. (A middle aged man)

The overall result of the impact of HIV and AIDS was a decline in agricultural production and off-farm sources of livelihood. The erratic rainfall in the geographical area of focus in this study has also contributed to food shortages but this was further exacerbated by the situation brought about by HIV and AIDS. Results indicated that families were surviving on one or two meals only each day.

4.8 Impact of HIV and AIDS on Zungwi Vlei

Overview of the impacts of HIV and AIDS from a questionnaire baseline survey carried out with forty-two Vlei members revealed that there was general consensus among community members of the impacts of HIV and AIDS on their community. Ninety six percent of the respondents said HIV and AIDS directly affected their productive activities. Another ninety four percent of the responses reiterated that HIV and AIDS had negatively affected productivity and had reduced work rate on the Vlei project. A further seventy two percent of the responses said HIV and AIDS had increased the death rate in the community and 96.4 percent said life expectancy had been reduced to forty years.

To add on, Vlei members gave the following reasons tabulated in a table 9 on how HIV and AIDS had impacted on them;

Table 9: Reported impacts of HIV and AIDS on Zungwi Vlei community

HIV and AIDS impact	Percentage (%)
Reduction in work rate due to increase of death	33.3
Enormous productive time spent on care-related roles	14.6
Resources of agricultural inputs diverted to patient care	14.6

It can be observed from the Table 9 that reduction in work rate resulting from the growing numbers of deaths was viewed as a major impact by the largest proportion of respondents. One respondent expressed the following, *“When my sister was sick, we took her to hospital and I could not do my productive work because I had to make several hospital visits and I also had to take care of her at home when she got discharged from the hospital till her death”*.

A second set of questionnaires administered to the Vlei community further revealed the impacts of HIV and AIDS at the household level. 13 out of 33 respondents openly acknowledged the presence of PLHIV in their households² and among their relatives, indicating that some were already deceased. The remaining 15 respondents said they had not had PLHIV at the household level, but said they had been affected by many funerals in the community that prevented them from going about their productive work. A focus group discussion held with members of a control Vlei (an undeveloped Vlei 4km away from the Zungwi Vlei) revealed that HIV and AIDS-related illnesses had resulted in many deaths resulting in negative effects on Vlei productive activities.

Below is table 10 which highlights the extent to which productive activities have been affected at household level.

HIV and AIDS impacts on productive activities	Percentage %
Too many deaths taking up time meant for productive activities (mourning, burial, recovery of families)	18

² Verified using the WHO HIV clinical staging of HIV

Reduced work rate	14
Not affected	12
Resources meant for agricultural inputs diverted for caring expenses	6
Loss of workmates and reduction in the number of people available for productive activities	4
Death of a breadwinner (resulting in absence of income to purchase agricultural inputs, food, pay for fees, pay for labour etc)	2
Failure to conduct any productive activities	2

Table 5 shows that more people were directly affected by the impacts of HIV. The majority of respondents had noticed the increase of deaths in the community. However, its also good to not a substantial number of respondents contends they had not been affected.

Economic impacts of HIV and AIDS in households

HIV and AIDS have economic implications for households. AIDS resulted in the depletion of resources and erosion of savings. Records from the home-based care programme revealed that HIV and AIDS were a long illness (range of illness of PLHIV being 6 months to 10 years). During this period, the patient requires medical attention and a good diet and, according to 86 percent of households interviewed, these required money. Thirty-five percent of households with PLHIV interviewed said they had already used all the money they had and nine had even sold livestock in order to raise money for medical expenses. Testimonies from home-based care facilitators also alluded to the point that families with terminally ill PLHIV spent all they had, and some even ended up selling assets in a bid to raise money for the care of their PLHIV.

Loss of household productivity and reduction of labour were also other problems. A case of one widow who is now deceased revealed how much productivity could be reduced. With a dead husband and a daughter who had been married and gone to stay with her husband, she had to engage in most productive activities all by herself. Her other children were young and were of school-going age and so could not do much

work.

Funeral and mourning costs have further reduced household income in households. Households that experienced death, though they got some help of one form or another, still had to bear most of the expenses such as transporting the corpse from the hospital and purchasing of the coffin. Other community members also had to bear the brunt of paying for all the necessary mourning costs that had become mandatory so that households are cushioned from some of the expenses. Recently, these costs included a standard cup of mealie meal and Z\$20 000 (equivalent to US\$0.5). With an average of eight funerals every month, this could mean a lot of money for households who already have other expenses to meet.

Care giving role

In Mutambi Ward, Zvishavane, the inordinate amount of productive time dedicated to care giving roles was contributing significantly to low levels of food security. Narratives with family care givers revealed how productive people had to spend an average of six hours fulfilling the care role at the expense of productive duties. Some of the family care givers had virtually stopped engaging in productive activities, particularly in situations where the patient got terminally ill and required more intensive or dedicated care. In some cases, absence from productive activities stretched for periods way over two months and this particularly affected women who largely executed the caring roles. The situation was made worse by those who left the urban areas when they got seriously ill, and returned to the rural area to be cared for. This had significant long term effects on agricultural production levels, and consequently on food security in the community.

Responses from questionnaires administered on members of the Zungwi Vlei scheme revealed how much the care-giving role was taking up their productive time. The care-giving role had become a major occupation in households with ill people. One respondent said she stopped attending to her agricultural activities because she had to look after her aunt. *“My aunt died due to an illness suspected to be HIV and AIDS. A lot of my time was stolen during the time of her illness, which saw my productive and reproductive activities highly reduced”*. She went on to say in the end she exchanged the care role with her mother-in-law so that at least both of them could find time to do

their work. As a result of this, it took longer for her and her mother in law to complete tasks. Whether exchanging the care role with her mother-in-law went far enough in helping her go about her Vlei activities was not very clear. HIV and AIDS have resulted in women facing competing demands for all the activities they are responsible for and for the care of family members suffering from AIDS related illnesses. The care role is largely a female role in Mutambi Ward, with men admitting they do not involve themselves in caring activities. Cultural inhibitions prevent them from offering intimate care to anyone except their wives and they are often forced to call in female children, relatives or even neighbours to help. The care-giving role gets more demanding as the patient gets worse. Observations made on the number of hours spent on a patient in a day varied depending with illness and intensity of the disease. On average, according to home-based care facilitators, family care givers spent an average of four hours when the patient was not too ill, and eight hours or more when the patient had become terminally ill.

Overall, from the time the project commenced more than 60 deaths have directly affected Vlei activities. These were deaths of Vlei members, Vlei project family members and members from the three surrounding villages and these are Virimayi, Mwedzi and Guti. According to responses, 62 percent of these deaths were HIV and AIDS-related deaths. This has amounted to more than one hundred and eighty person-hours (Vlei members worked for 3hours each time they went to the Vlei) lost by the crop project members. These are frightening figures that are likely to soar, given the number of members of the community in the home-based care programme (on average 85 each month), without even considering those community members who were ill but not in the programme, those who were in town and who later were brought to the village for burial after death.

A case of a man in the chief's lineage who had died in 2005 caused the loss of many hours of productive activities for the community. The mourning period lasted for 5 days in accordance with the customarily stipulated five days for mourning (known in Shona language as "*mahakurimwi*") for members of a chief's family. This death occurred five days before the Vlei had to be opened for cattle grazing since plot holders were expected to have harvested all their crops. Thus those who had not done so risked having their crops destroyed by cattle.

Absence from productive activities

Illnesses and deaths in the community were preventing community members from going about their productive activities. Some had been rendered permanent family care givers and had to send other family members to cover up for their activities. Others, on the other hand, had to attend to regular burials in the community. Productive activities (activities engaged in to raise income for family use) ranged from cross border trade, selling, agricultural activities, carpentry, building, piece work, formal employment and gardens. One male cross border who was interviewed had indicated traveling to Botswana on the morrow. It was later on established that he had failed to do so because of a funeral that had occurred in the village he stayed in. He said he had to make alternative traveling plans.

Absence from agricultural activities was also seen to be as a result of attendance to memorial services and or “*mabira*” in the community. Memorial services were very popular with Christians whilst “*mabira*” were popular with traditionalists. Memorial services were usually held between two and six months after one had been buried. The same period also applied to “*mabira*”. These services occupied the whole day and were usually set aside for days such as Thursdays and Saturdays. Coincidentally, these days were also the days reserved for productive activities in the community (Wednesday was referred to as day set aside for rest termed “*Chisi*” in Shona language and Sunday and Saturday for the minority were set aside for church services and no productive work was indulged in by Christians).

Absence from agricultural activities

A Vlei diary was recorded from 29 October 2004. Vlei members only attended to three out of a total of five Fridays in 2004 and to thirteen Fridays out of a possible twenty-one in 2005. The Vlei diary from 28 October to date has also been observed. Out of a possible 23 Fridays, project members have been present on only 12 Fridays, which was about half the number of Fridays. Funerals and illness largely prevented Vlei members from attending to their activities on these days. Also from the Vlei diary, attendance fluctuated considerably. On average, 16 people attended to Vlei activities out of the 42 registered members. This alone shows that the majority of the project members did not attend to their Vlei activities when they were meant to. This highlights the amount of planned work that remained not covered.

The impact of absenteeism due to illness and death on the non-Vlei community has also been adverse. A funeral in one of the nearby villages in the community meant no work for surrounding villages. According to questionnaire responses, 94 percent of the respondents said they had been disturbed by funerals more than 10 times. These respondents said they had children of school going age and had no replacement labour to cover up when they attended burials. Some 54 percent of the same respondents said they had formed working groups as a result so that when one had failed to cover up their work, they would call on the other members of the work group, with the beneficiary taking on the responsibility of feeding the working party the whole day.

Death and burial register

A register of deaths was recorded from March 2005 to March 2006. The death register was used to assess the average number of people who died in a month and determine the number of days it takes before burial. The number of deaths and burials included even those who died in town and were ferried to the rural area for burial. These deaths and burials resulted in absenteeism especially for those who did not have replacement labour. The death register was recorded during the agricultural season and the number of deaths shows how much agricultural activity in both upland and wetland farms were disrupted. The table below shows data compiled from the death register in November 2005.

Table 11: Community death register for November 2005

Sex	Age	Death date	Burial date
Male	50	01/11/2005	02/11/2005
Male	54	04/11/2005	05/11/2005
Female	43	08/11/2005	09/11/2005
Male	Below 25	10/11/2005	11/11/2005
Female	48	13/11/2005	15/11/2005
Male	47	14/11/2005	25/11/2005
Female	41	17/11/2005	18/11/2005
Male	38	21/11/2005	23/11/2005
Female	44	25/11/2005	26/11/2005

It is clear from the table above that for the month of November 2005 alone, a total of nine deaths had occurred. This number is far too high for such a small community. It can also be observed that, invariably, all those who died belonged to the economically active group, and frequently those who were in their prime years of productivity. There was a gender balance in the deaths recorded, the males slightly outnumbering the females.

Reduced life expectancy

According to questionnaire responses administered to members of the Vlei project, life expectancy in the community had dropped to 40³. According to them, it was the old who were surviving and the young and productive were dying. In separate FGD's held in different villages, life expectancy varied. In one village it was said to be 45, in the second it was 43 and in the third it was as low as 38. Participants of these FGD's also mentioned the point that it was mainly the economically productive who were dying and leaving children and the old.

4.9 Change of roles and responsibilities

Traditionally, in the Shona culture, certain roles and responsibilities are inherently associated with males or females. Women were more restricted to the household duties, care giving role, general family upkeep, and working in the field or garden and so on. When working in the field, men were traditionally responsible for cultivating using oxen, using the cultivator and other big implements. Women would use small implements such as hoes to till and do more of the light duties (excluding thatching the huts, brick moulding, transporting bricks with wheel barrows). Now with the loss of family members, or even the illnesses in most families, this has changed. There is now a high flexibility of roles and responsibilities. Roles and responsibilities, according to responses from Mutambi community members, have changed from household to household. Roles and responsibilities have been largely allocated depending on sex (male or female), age, tradition and available labour. But then in some households, there are home-based PLHIV, or a deceased family member(s). The patient or the deceased (before death) will have duties that are specific to them. Because these households cannot afford to hire labour, they just take over the

³ Table 5, page 58 shows the same result.

patient's duties or the deceased's (duties that would have been conducted by the deceased if they had been alive) duties.

Duties were now discharged based on the available labour. Now you could find women doing inherently male duties and men participating in traditionally female roles. Two reasons resulted in the changes of roles. The first reason, according to 25 respondents, is because of the need for such a change following the death of a family member. This forced the family to allocate another member. The second reason alluded to by 38 respondents was the presence of an ill house-member. When one was ill, one was helpless, and therefore needed help from others. The situation was worsened by the fact that an ill person frequently required someone to care for them. This meant two people being prevented from being productive. Therefore labour in such situations was allocated according to the available labour irrespective of the sex of an individual. The care role which also had largely been a female role was slowly being taken up by men who said culture prevented them from caring for female children and relatives, but they could care for their wives and male children or relatives only. The home-based care programme in the ward also reflected that some men were willing to provide the care-giving role. The programme had a total of 20 facilitators and three of these were men. These men did the same duties as women.

Besides the change of traditional roles and responsibilities, women in Mutambi Ward had become empowered and had been engaging in multiple income-earning activities and taking charge even in agricultural activities. According to women in focus group discussions, women had realised how much they had relied on men to bring all the money into the household and when the spouse either succumbed to HIV and AIDS or passed away, they became destitute and it took long for them to get back on their feet.

Impact of HIV and AIDS on children

HIV and AIDS led to high dependency on children as sources of labour, with households admitting to using children as labour sources. This was largely necessitated by the death of household members who were in their productive years. Most of the families affected could not afford to hire labour so they ended up relying on allocating duties to children.

Orphanhood

According to community members, HIV and AIDS had resulted in orphans. Being an orphan in this instance is having one parent or both parents dead. This was because of the many deaths that mainly affected the productive people of the community, and whose age ranged from 30 to 55. This was confirmed in the death register in which the ages of the deceased were recorded. Responses also showed that even for those who died in town, and had no other relatives to care for their children, their children were brought back to the community to be cared for by relatives in the community, especially by grandparents. Deaths had also resulted in child-headed families and these had been receiving support from the community and from donors. The community seemed to be coping well with orphans because, according to responses from one focus group discussion, they were yet to see child-headed households. All orphans had been absorbed by the extended family. Additional responsibilities on families were inevitable because of the reversal of urban-rural support networks as the urban sick 'returned' to rural areas to die and be buried, and their orphans are sent to relatives in the rural areas. This prevented these children from becoming destitute or from living on the streets.

4.10 Responses and coping strategies to HIV and AIDS in the household

Households responded to and coped with the direct and indirect impacts of HIV and AIDS in a variety of ways. Obviously, the most direct impact of HIV and AIDS is on the individual's state of health, while the less direct impact is on household resources. Both have implications for behaviour in terms of health-seeking interventions and resource mobilisation. In this section we examine the ways in which households responded to these two.

Mobilisation of financial resources at household level for home care

Due to the financial strain brought about by HIV and AIDS, households had devised ways of mobilizing for financial resource to ensure they have money available for use.

Table 12 below highlights how households were mobilizing resources for use at the household level.

Table 12: Mobilising resources at household level

Source	Percentage (%)
Foregoing essential services i.e. medical care, agricultural inputs, education and clothing	32
Sale of productive and nonproductive assets	26
Depandance on relatives in urban areas	24
<i>Maricho</i> (piece work)	16

Overall, households employed different and varied ways of mobilising financial resources. It is however clear that the methods adopted for resource mobilisation were not sustainable. When savings are finished, the household, or when all assets available for sale are finished, the household is put in a difficult position. And when relatives who usually provide financial assistance do not have at a time when money is needed, the household is put in a difficult position.

4.11 Coping with illness

Relatives and neighbours

More than 95 percent of PLHIV in the home-based care programme come from families that were rated as 'poor' by facilitators. By poor, the facilitators meant these families could not afford to seek medical treatment, and could not afford to buy medication for the patient. These households could also not provide the material support required by the patient such as soap, creams and jellies, food and others. The majority of households had financial limitations and, according to 65 percent of those who had PLHIV, they got financial support from relatives especially those in town who provided consultation fees as well as medical fees. Households also relied on relatives and home-based care facilitators for patient care and support. Households also relied on support from different partner organisations that provided support in different ways.

Role of family caregivers

The greatest burden of the care-giving role in more than 75 percent of households with suspected PLHIV falls on women. Family caregivers were playing a large role in looking after ill members of the family. They got additional support from the home-based care programme (for those that were in the programme), and those with PLHIV not in the home-based care programme, mainly relied on family members and relatives to help out. Family caregivers were largely responsible for all patient care including cooking, cleaning (of the patient and the patient's clothes and blankets), feeding of patient, bathing of patient and even carrying or supporting of the patient when taking them out for some fresh air. All the financial requirements of the patient were largely the responsibility of the whole family, relatives included. They had to provide money for medication when need for it arose and also money for consultation fees. They also had to provide a balanced diet for their patient or at least something for the patient to eat during meal times.

Treatment of PLHIV

Some 38 percent of respondents preferred use of medical institutions over other alternative treatment modes. According to respondents, medical institutions were proving to be too expensive and more people were beginning to rely on traditional healers. Medical institutions, besides sending PLHIV home (this was observed by the researcher on two occasions and those sent home did not live for more than two weeks) for home care required consultation fees, admission fees and money for medication. For those with no relatives in town, it meant that, when a patient got admitted, had to travel regularly to town to go see the patient and this cost them a fortune. More than 60 percent of families indicated that even though they preferred medical institutions, they were proving to be too expensive for them so they ended up opting for traditional medicine.

Role of traditional healers

Respondents were requested to indicate the form of treatment they opted for, and their responses were tabulated. Below is a table that shows the percentages of respondents who opted for each of the four different forms of treatment.

Table 13: Preferred community health seeking behaviours

Mode of treatment	Percentage (%)
Medical institutions	38
Traditional healers	32
Faith based healing	18
Self medication	12

Table 13 shows that a combination of treatments, particularly traditional and modern medical institutions, was preferred by most households. Some 32 percent of respondents contended that they relied on traditional healers for treatment of PLHIV. According to responses, most people in the community preferred going to the traditional healers because, as an alternative, they offered advantages over the other health services. For instance, respondents mentioned that traditional healers did not test for HIV so there was no way one would know that they were HIV positive. They also believed that traditional medicine was very helpful and prolonging one's life. They went on to say people feared going to the hospitals because when one was very ill, hospitals suggested that a patient takes an HIV test. Traditional healers interviewed mentioned that in the past 4 years, they had been receiving a lot of PLHIV, mainly those with chest pains, diarrhoea and TB. Traditional healers were favoured over medical institutions because they were locally based so no transport costs were incurred. Traditional healers also charged comparatively lower fees. In most situations though, a combination of the four modes of treatment was used.

Contribution of Churches

Faith based organizations were involved in HIV and AIDS activities in Mutambi Ward. They were mostly involved in activities relating to AIDS prevention as well as care and support at the community level. The most common activities included provision of education for awareness, home care, counseling, food and material support and support for orphans. According to responses, churches in the ward had limitations in what they could do to help the affected but were making significant contributions in helping with home care, productive activities and counseling, particularly to those who would have lost their loved ones. Their help was particularly seen in activities that did not involve material or financial resources. However 28 percent of community members felt advocacy by churches on behavior change was

not leading to much behavior change. Members of the community appreciated home care but in some cases resources and skills for extensive home care programmes were lacking. Counseling, food or material support and support for orphans were also rated as successful in Mutambi Ward but in some cases they were not very effective due to high level of stigmatisation and lack of skills (in the case of counseling) or lack of material and personnel resources (in the case of support).

Churches in Mutambi Ward delivered a number of messages to their congregations and to the general community on HIV and AIDS. The most common of these messages were abstinence among the youth, widows and widowers, faithfulness, the importance of love, care and support for those infected, the importance of getting tested and disclosing one's status, using condoms, and not discriminating against those infected.

The success of these messages varied by faith. Those interviewed rated faithfulness and love, care and support for the infected as the most successful. Messages of abstinence were more successful for some faiths than others, as leaders and community members saw that few were following this strategy in many of the faith groups interviewed. The message to get tested was less effective because of stigma and limited testing facilities in some cases. Using condoms was seen as a successful message by a few churches but for most they either felt it was an inappropriate strategy or that it often failed. Not discriminating against those infected was more successful in Uganda than in South Africa, where stigma remained much higher.

Some churches were also involved in faith based healing and some churches believed they could heal HIV and AIDS. One particular church did not permit its members to use medical institutions as there was the feeling that all healing was "from above", meaning from God.

Nutrition of PLHIV

According to 68 percent of family care givers, providing a balanced diet for PLHIV was very difficult. This was mainly because of drought that had hit the community in the last 4 years. Family care givers said they largely gave their PLHIV porridge, *sadza* (thick porridge) and vegetables that are in season. According to them, PLHIV always

complained and said they wanted meat but one respondent said ‘*AIDS is a disease of meat, if we listen to our PLHIV and give them meat whenever they request for it, then we will by now be left with no chickens and no livestock in our homesteads*’. Without the help of partner organisations and well wishers, family care givers said their PLHIV would not die of AIDS but of hunger.

Behaviour change as a coping strategy

During FGD’s and through questionnaire responses, community members said there was noticeable behaviour change in the community. People in the community have seen what the virus can do to a person and people are so grieved when people kept dying. This had led people to change their sexual behaviours. According to those who were not directly affected by the pandemic, 76 percent of respondents said sticking to one sexual partner had become a coping strategy for them.

Coping with labour demands

Table 14 shows how Vlei project members coped with labour requirements in light of absenteeism due to illness and deaths as a result of HIV and AIDS.

Coping with labour	Percentage (%)
Not coping	25
Not affected	20
Hire labour	17.9
Receive assistance from relatives	8.8
Children allocated duties	8.8
Working extra hours	5.9
Exchanging caring roles	5.9
All productive time and labour spent on care	2
Only work when the ill family member’s health has improved	2
Have replacements	2

Twenty-five percent of the respondents among Vlei members said they could not cope with labour demands. Those who said they were coping mentioned the following coping strategies; allocation of duties to children (8.8%), securing help from relatives

(8.8%), getting hired labour (17.9%), working extra hours (5.9%), and exchanging the care role with other family members (5.9%). Some 20 percent, however, indicated that they were not affected at all.

Case Studies of household responses

Household 1: A widow (now deceased) who was a TB patient in the home based care programme mentioned that she was relying more on child labour as she was not feeling well and because her husband had died from TB. Her eldest daughter was married and had moved to the neighbouring district of Mberengwa together with her husband. The other children were all of school going age and only helped her over the weekend and during the holidays. She had been forced to decrease the acreage she tilled because of the limited labour and limited inputs available to her, and she was renting out the other part of the field to augment her income. She had no other source of income and two of her children had their fees paid by the Basic Education Assistance Module (BEAM). Her married daughter helped her once in a while, but she said the last she saw of her was when her husband had died. According to her, the home-based care programme had been helping her because of the regular food handouts that she got from them. She and her husband had also been given non-food items such as buckets, cups and towels for use at the onset of the programme in the ward. What she still needed help with was money for medication, school fees, food, and help with inputs and labour.

Household 2: A man with TB was doing well because he had sons who worked in town. The sons were providing him with money for most of the medication and the food he needed. He was a carpenter by profession but since he got ill, his brother had been helping him with the trade. He had received limited benefits from the home-based care programme and these were maize meal, beans and cooking oil. His wife was the sole family care giver and she said care-giving had become another role for her. This family was coping with labour because of the presence of more than eight people on the household who helped with productive activities.

Household 3: The respondent mentioned that the home-based care programme had helped her significantly, especially during the first days it was launched in the community. She went on to say she benefited from gloves, medicines, linen savers

and she was also helped with patient care. She also reiterated that the home-based care programme had helped her with information on patient care and how she could protect herself from infection. Although she says while her patient was now late, she was grateful to the home based care programme because she was able, during the patient's illness, to cope with aspects of labour at her household and patient care itself.

Household 4: A man interviewed said he had been forced to venture into cross border trade after the death of two of his family members who had died from AIDS. He said before their death, they would bring goods from Botswana, South Africa and Mozambique some of which he sold on their behalf and he would get income from these. In a way, they were business partners and he reiterated that that the business plans had been disturbed. Now he had been forced to venture into this trade himself because this was his livelihood and he had to try and make a living. He had also wasted his savings and resources during their illness by taking them to medical institutions and paying their bills.

Community coping strategies

At the community level, there were also several coping strategies adopted by households in the face of the challenges and multiple demands placed upon them by HIV and AIDS. In this section we examine these coping strategies.

Community social support

In Mutambi Ward, community social support depended on several factors, mostly the existence and cohesion of communal or group activities. Traditional communal social support systems (extended families and non-formal networks) for reducing household stress were getting strained. In addition to labour effects, support in care and during time of bereavement, were noted to be part of support from the community.

Mutambi Ward community has been playing a role in helping affected households cope with the impacts of HIV and AIDS. With a high level of awareness of HIV and AIDS (revealed by the baseline survey) and its impacts, the community has been on the alert. These awareness levels have been raised at a community level by community leaders who took advantage of large gatherings to communicate

information on HIV and AIDS to the community. Groups from two local schools were at times called to teach, inform and educate through drama and role playing. Mutambi Ward community members also said they helped families with home-based PLHIV with household chores such as collecting water and firewood when they could. This they say they did because these families found it difficult to cope with labour because of the presence of an ill household member.

Interviews with community leaders revealed they were going a step further in fighting the pandemic. The table below highlights some of the activities community leaders were engaging in as a response.

Table 15: The role of community leaders in fighting HIV and AIDS

Role of community leaders	Activity
Information dissemination	Disseminate information to the community on HIV and AIDS prevention and living with HIV and AIDS
Source for donations (food and money)	Source for food from NGO's and distribute the food particularly to PLHIV in the home-based care programme
Work with NGO's /Stakeholders	Spearhead all activities by NGO's such as payment of fees for AIDS orphans (BEAM) distribution of food by WAACs
Facilitators	Organise groups For people living with HIV and AIDS so that they can share experiences and give each other encouragement
Fighting stigma and discrimination	This they do by advocating against stigma and discrimination at community meetings

Community field

A community field was set aside for those with who are HIV positive or those with AIDS in Mutambi Ward. In 2004, community leaders, in agreement with community members, set up a field meant to benefit households with PLHIV. Inputs for the field had been secured by the leaders of the community from different organisations some of which include GMB and AFRICARE. Mutambi Ward community members provided their labour on this field and the outputs (which are harvests) were shared amongst households with home-based PLHIV. The scheme was meant to help provide

a balanced diet for those who were positive so that they could prolong their lives and be able to work for their families. This scheme collapsed in 2005 because of failure to acquire inputs for the scheme.

Change of cultural norms and values

HIV and AIDS impacts had an altering impact on some cultural practices like mourning practices and burial rites. In Mutambi Ward, before the emergence of HIV and AIDS and before the increase of deaths in the community, when a community member died, the community respected at least three mourning days. Sometimes, a family would decide to wait for relatives travelling from other towns, who would want to pay their last respects to the dead. This meant that when a member of the community died, people were not allowed to go about their productive work from the day the person died to the day she/he was buried. Even after burial, there was still a period set aside when people refrained from work or other productive activities. Several people had been dying and other deaths had been occurring simultaneously and community members had been spending the bulk of their time attending funerals. As one respondent put it, every time children saw them going out, they would ask '*Asi muri kuenda kumariro zvakare?*' *Are you are going to a funeral again?*).

The chief and other community leaders, in agreement with the community changed the practice of three or more mourning days. This was because time spent at funerals led to the suspension of progress in different activities by community members. A new policy was therefore introduced. After the death of one of them, the community were allowed to go about their productive activities before burial (when body is still at the mortuary) and resumed work soon after burial. This meant that the only time community members invested was that for attending the burial. With an average of eight deaths a month in the ward (according to questionnaire responses), an inordinate amount of productive time was being spent at funerals. If the three mourning days were still to be followed, then this would result in the loss of a total of 24 days a month. This policy also helped in terms of money spent at the funeral by a household and the contributions to be made by other individual households in order to help the affected household. This initiative was meant to help the community cope with labour and time lost whilst at funerals. Although this is an idea that came from the community, it benefited both the household and the community level. HIV and AIDS

have therefore forced Mutambi Ward to adjust burial rites in terms of time and money spent for those affected households to cope with economic and labour pressures resulting from HIV and AIDS.

External support

A survey of the institutions helping the community to cope with HIV and AIDS was made, and the results have been presented in the table below.

Table 16: Institutions and organisations supporting Mutambi ward community

Institution	Activity or form(s) of support provided
1. Bethany	Paid fees for orphans and also provides them with clothes and blankets. Also provides food to the home-based care programme.
2. Basic Education Assistance Module (BEAM)	Paid school fees for orphans (with both parents dead)
3. Lutheran Development Services (L.D.S)	Provided school fees and uniforms to orphans
4. Dananai	Looked after those who were suspected to be positive. Trained 12 community members to become facilitators of the home based care programme and provided kits for them. Gave out buckets, soap, food, cups and body cream or jelly to those suspected to be HIV positive.
5. HOPE	Paid school fees for orphans
6. Betseranayi	Assisted orphans with payment of school fees. It also funded the home based care programme in the ward. It elected 9 community members to be trained as facilitators of the home based care programme, it also built ventilated toilets for community members.
7. UNESCO	Paid fees for orphans.
8. GTZ	Provided material for use for the home based care programme. Some of this include food, body cream and jelly, towels and intends (funds are available for this purpose) to buy bicycles, linen savers and beans for the programme.
9. D.A.A.C	Distributed food for PLHIV in the HBCP on behalf of the government. They also gave gloves, body cream and jelly, medicine, to be used at the local clinic, facilitators and family caregivers.

Home-based care programme (HBCP)

In Mutambi Ward, a home-based care programme was introduced by a local non governmental organisation in July 2003. A total of twelve Mutambi Ward community

members (1man and 11 women) were chosen by the community during a community meeting where everyone in the ward had been invited to attend. The HIV status of those who were chosen is not known. These were then trained to become home-based care givers. They were selected from the different villages in Mutambi Ward. In 2004, due to the increase of home-based PLHIV, another nine community members were trained to join the pool of the twelve who were already discharging their duties as care givers. Of these, 2 were males and 7 were female. However, during the study, the programme lost one of the female home-based care givers who succumbed to illness. These community care givers, though voluntary, were largely recognised by the community as making positive contribution in helping families with affected family members in the care giving roles. According to the care givers, what drove them to executing these duties even without remuneration was that they were working in their home community where most people had ceased to be just neighbours, but family.

An assessment of the home-based care programme was done by the study because 60.5 percent of those with suspected PLHIV at the household level mentioned the HBCP was one of their coping strategies. The home-based care programme was introduced to the community in July 2003 by a local Non-governmental organization (NGO) called Dananai. A total of ten community members were trained to become home-based care facilitators. These home-based care facilitators are all local people who volunteered their labour to help households with suspected. It was then realized that these ten facilitators were not enough to cover all the villages in the ward, so two more were added to bring the total to 12 facilitators. Another ten home-based facilitators were also trained during the same period by a different organization called Betseranayi. In total, the home-based care programme in the ward had 21 facilitators till one facilitator passed away in January 2006. These facilitators include three males and 17 females.

Home-based care facilitators work a total of three days a week. These were not fixed though because they varied according to the number of PLHIV they had at any given time. The number of PLHIV per facilitator varied from four to 12. Facilitators worked by making visits to all the households they had PLHIV in. Their duties included patient check ups, demonstrations of bathing a patient in bed, administering medication on PLHIV, information dissemination, help with reproductive activities

and recommending of other PLHIV into the programme. During the data collection exercise, it was revealed that the number of PLHIV in the programme was not fixed and varied from month to month. Variation was caused by the death of some PLHIV, exit by other PLHIV who recovered and emergence of new PLHIV in the home-based care programme. The number generally varied from 120 to 150 PLHIV at any given time. Data collected at one time revealed a total of 128 PLHIV in the programme. Seventy-four of these were females and 54 were males. The data presented in Table 17 below is information relating to the marital status of PLHIV.

Table 17: Marital status of PLHIV

Marital status of PLHIV	Number of PLHIV
Married	57
Single	14
Widowed	42
Divorced	3
Children	12

The table reveals that the majority of the PLHIV were married individuals, with the second largest group being widowed individuals who, obviously, were at one time married too. Single individuals and children were comparatively fewer because the two categories comprise younger people. Given the dynamics of the progression from HIV to AIDS and finally to death, this is expected.

On average, illness duration varied from 6 months to 10 years. The age range of PLHIV was four years to 82 years. The period of care largely comprised the time when PLHIV were grappling with opportunistic infections. Opportunistic infections mainly affecting the PLHIV were recorded from the home based care programme, and are shown in Table 18 below.

Table 18: Opportunistic infections recorded in Mutambi Ward

Opportunistic Infection(s)	Number of PLHIV
Tuberculosis	51
Chronically ill (a combination of several OI's presumably the AIDS stage resulting in one	16

being bedridden)	
Diarrhoea	33
Skin rashes and body weakness	12
A combination of TB and diarrhoea	14

The above opportunistic infections were obtained from records of Home Based Care workers and have been presented as they were from the records.

Some 60.5 percent of the 33 questionnaire responses indicated that the home-based care programme helped them to cope with caring activities at the household level. This help was in the form of provision of basic food stuffs (kapenta fish, cooking oil, salt, mealie meal), sanitary products (gloves, soap, detergents, linen savers (napkin-like cloth with a plastic bottom for diarrhoea PLHIV), receptacle materials (buckets and dishes), help with patient care and help with knowledge of proper care of PLHIV. At the time of the study, the exact number of Vlei members in this programme was not known. Cases that were known did not distinguish members of the broad ridge and broad furrow project from non-members. Responses from community members indicate that the home-based care programme has been a very good initiative in this community. Its major limitation was that it did not cater for everyone. According to these responses, the facilitators working in Mutambi Ward were still very few and yet the PLHIV that needed their services were many.

As raised by facilitators and family care givers, care and support for terminally ill PLHIV in the ward was particularly difficult because of limited resources. According to PLHIV interviewed, family care givers and home care facilitators, the main expressed needs of people living with HIV and AIDS are common drugs, financial help, good food (meat, eggs, milk), emotional support, and empathy from health staff. These were reported to be inadequate or in limited quantities. Drugs were too expensive and some households had resorted to not buying them as part of their coping strategy, or to resorting to traditional herbs from traditional leaders.

Coping with loss

Death was frequent in the community. With an average of 8 people dying each month,

the community had to adapt to coping with death. When there was death in the community, other community members would contribute \$20 000.00 (US\$0.5) per family and a cup of mealie meal for funeral expenses in a bid to cushion the affected family from enormous funeral expenses. Firewood and water to be used at the funeral was also collected by those who would have attended the funeral. A questionnaire administered revealed the following as ways by which community members coped with death-related impacts: funeral contributions (40%) memorial services (55%) and *mabira* (5%). *Mabira* is a traditional ceremony conducted to bring the spirit of the dead back to the household. So the family does not see the death as loss but they believed the spirit of the dead person was living amongst them.

Burial societies

Burial societies have helped community members to cope with loss of their loved ones. Burial societies in Mutambi Ward amount to three. They mainly helped households with costs incurred at a funeral. In 2004, based on results from the baseline survey, 12 percent of the people were members of the burial societies. In 2006, the figure has risen to 38 percent. Burial societies according to respondents help by buying coffins, providing food and mostly providing company during and after the funeral.

4.12 Disclosure of HIV status in Mutambi Ward

According to the community, disclosure is openly disclosing one's HIV and AIDS status. Responses to a questionnaire survey revealed that 28 percent of people disclosed their status only to their immediate family and the rest 72 percent did not reveal their status. They were indications of indirect disclosure by individuals in the community. Eighty percent of respondents thought that all those in the home based care programme had disclosed to a great extent that they are HIV positive. One of the focus group discussion held revealed that they were very few disclosures as there was consensus to the following statement by one of the participants:

No-one discloses their HIV status. We haven't heard anyone disclosing publicly, we only hear of disclosures through the person they will have disclosed to. People only disclose when they have some form of help in the community e.g. when Dananai came in with the home-based care programme. They were giving buckets, dishes, kapenta, washing soap, lifebuoy, cooking oil and mealie meal. Then, that's when we had people coming out to disclose.

Disclosure, according to them, was motivated by direct benefit accruing from openly disclosing one's status.

Below is Table 19 that shows the number of people who indicated that they would disclose their status if they test HIV positive. In total 76 people were asked.

Table 19: Participants' preparedness to disclose HIV Status

Disclosure Status	Percentage (%)
Would disclose	12
Would not disclose	78

Focus group discussions, questionnaire responses and interviews revealed that very few people would disclose their status. This is also based on the fact that 78% of the respondents said they would not even go for Voluntary Counselling and Testing for fear of finding out that they may have HIV.

Possible reasons for nondisclosure were also given by the community. Some of the reasons include the following: people do not even know their HIV status because they will not have gone for testing (32%), HIV and AIDS are still largely associated with prostitution so people are ashamed to disclose (40%), others are in denial and still associate HIV with witchcraft (28%). Others said certain attitudes prevented people from disclosing their status and some of these include people gossiping about those who are infected, sex as a source of the disease, discriminating ('*kusema*') those who are positive, and predicting death on those who are suspected or who will have disclosed their status.

According to participants from the Vlei community who participated in a focus group discussion, there were a few disclosures in the community. People opted not to disclose in most cases. This was slowly fading though because of the new initiative in the community. Community leaders in their work with donors had come up with a new initiative that helped more people to disclose their status. Only those who had gone for testing and who brought proof of their positive status got help from donors.

This was because support available could only cover a limited number of people, so for this support to benefit the targeted beneficiaries those who had been tested and found to be positive were asked to bring proof of this. This was compulsory. As observed on one of the field trips, only those who had brought proof that they were positive or had a positive patient at home benefited from food handouts that included 10 kg of maize meal, 5 kg beans and 2 litres cooking oil.

A total of 12 people attended to one set of a FGD that had been arranged and when asked if they would disclose, and their responses were noted. Table 2 shows responses transcribed directly from FGD participants when asked whether they would disclose their HIV status or not.

Table 20: Participants' preparedness to disclose HIV Status – FGD Responses

Participant number	Reason(s)
1 (Female)	I would only disclose if I am told at the clinic. I will just go home and tell my children. I will disclose only to my immediate family.
2 (Female)	I would disclose to my relatives only so that they know how to care for me.
3 (Male)	I will not disclose because HIV and AIDS ' <i>chigwere chinonyadza</i> ' (a disease that brings shame) in Shona language.
4 (Female)	I will disclose to my relatives only if I get seriously ill so that they can help me.
5 (Female)	I will not disclose because it will come out through its signs and symptoms anywhere.
6 (Male)	I will not, I will just die quietly. My relatives will be troubled and my wife will also start to think that she is also HIV positive.
7 (Male)	If I get to know my status I will disclose so that I can get help from my relatives and people in the community.
8 (Female)	I will not disclose because the way you acquire the disease ' <i>inonyadzisa</i> ' (is shameful) so by disclosing people get to know what you did.
9 (Male)	I will not disclose. People will start seeing me wasting away and then they will know that I have the virus. So they will get to know eventually.
10 (Male)	I will disclose to people. That way I will prevent myself from spreading the disease.

11 (Male)	I will not disclose, I will not even go for testing, ' <i>ndinofira murima</i> ' (I will die in ignorance)
12 (Female)	I will not disclose, I will be too ashamed to do so.

In table 20 above, the indications are that there is balance on the number of males and females who would disclose their HIV status. However, for those who say they would disclose, the main reasons are for material gain or do they would get support from relatives when they become chronically ill.

Benefits of disclosing one's status

Provision of support to individuals infected by HIV or AIDS is usually based on a certain level of disclosure. For instance, churches were providing spiritual support and material support only to those people who would have disclosed their HIV status. Other organisations such as the District AIDS Action Committee (DAAC) had also adopted the same principle because they said they wanted their support to benefit the intended beneficiaries. During distribution of food and medicines, they would require one to provide proof that they had gone for testing and had tested positive. However, due to the absence of a Voluntary Counselling and Testing (VCT)⁴ Centre in Mutambi ward, getting proof of one's HIV status was a challenge as it meant one has to travel all the way to Zvishavane town. The home-based care programme in the ward was also only meant to benefit those who were HIV positive and according to 88 percent of the respondents, being in the programme was in itself a form of disclosure of one's positive status. Though to a large extent some of the beneficiaries may not have been HIV positive, Home based care facilitators tried to ensure they catered for those with HIV or AIDS by looking at the clinical symptoms of HIV before admitting one into the programme.

4.13 Stigma and discrimination

The two terms, stigma and discrimination, were first defined by the community in terms of how they understood them. They were both seen as negative responses to those who are HIV positive. Stigma was defined as '*kushora*' or '*kusema*' translated as '*showing disgrace and disgust*' towards a person because they were HIV positive

⁴ However, Dananai and Betseranayi (local NGO's offered mobile VCT services on two occasions during the study period.

or suspected to be HIV positive. Discrimination was defined as '*kusarura*' or segregation according to one's HIV status. The basis for these negative responses was a result of the way the disease was transmitted. Respondents believe it is transmitted through sexual activities by those believed to be loose or prostitutes. According to responses from 43 questionnaires administered to Vlei members, 12 questionnaires administered to home-based caregivers, 31 questionnaires administered to non-Vlei members and 10 questionnaires administered again to Vlei households 72 percent of PLHIV were receiving were being accepted by their families and the community. Reasons given for this are because the ill got proper patient care from their family members and were not treated differently from any other member of the community. 'Proper care' meant that they were given food at the right time, bathed frequently, watched over at all times, and treated like any member even though they were not well. Other community members, not household members, even helped out with household chores at these households and also helped out with resources when they could. Most of these respondents say they did so because in future it could be their turn so they did to others what they wanted them to do for them. One of the respondents said: "*Tinochengeta varwere zvakanaka, ativasemi nekuti hauzivi ramangwana. Pamwe mangwana ndiwe*" (Which is Shona language meaning "We look after the sick very well, and we do not discriminate them because you never know what tomorrow brings. Who knows, tomorrow it may be your turn".) Mrs. Tombi (not real name).

The other 28 percent, contended that the ill were mistreated and discriminated against. Reasons for this were because their utensils (plates, cups and spoons) were set aside only for their own use and no other member of the family could use them. In addition, people did not want to shake hands with them and did not want children to play close to them. To add to this, people said bad things about the ill, as was illustrated by the following example from the responses given: "*Paainakirwa tanga tisipo, iye zvino aakuda kutinetsa kuti timuchengete.*" In English language this means, "when he was having a good time, we were not together, now he wants to burden us with the care-giving role." (Mr Siso - not real name.)

Testimonies from home-based care facilitators indicated that PLHIV during the first days of the introduction of the home-based care programme in the community, did not

feel comfortable with them. But as time went on these PLHIV discovered that the caregivers were there to help them, and so they became freer with them. Three caregivers even indicated that others loosened up to the extent of disclosing their status. Although caregivers think because of opportunistic infections evident in some of their PLHIV, and the duration of patient's illness, they did not think all PLHIV in the home-based care programme are HIV positive or have AIDS.

The non-Vlei community raised different views when they were asked if PLHIV were discriminated against. Of interest is that some saw the good initiatives rendered to PLHIV as discrimination. For instance, others thought it is only PLHIV who were considered for food handouts. Others thought it was only PLHIV who were considered and taken up into the home-based care programme. The others held a negative view. They thought PLHIV were regarded as a problem and a burden whilst others thought the clinics sent these people away because they had an untreatable illness. Some said there was no discrimination even at beer drinking places as people were seen to be sharing mugs even with those who were suspected to be HIV positive. According to 60 percent of the people, discrimination was within the home and usually started when the patient became bed-ridden and other family members felt they could not use the same utensils with them.

According to responses from one village, stigma and discrimination only come from people outside a particular household. However, the family members treated their own well. According to them, it was ironic that people laughed at the other people in this community and said they were HIV positive yet they tried so hard to hide their own member of the family when they found out that the person was positive. They usually gave this patient all the care they needed till the person passed away. Others also even sold assets to get income to take the sick to the hospital, to buy medication and to provide them with a balanced diet. People still thought that it was embarrassing to disclose when you were HIV positive because those who were positive were still largely stigmatised and discriminated against and this disease was largely associated with sexual intercourse only. Despite being educated enough and knowing of other ways in which HIV was spread, people associated HIV and AIDS with sexual intercourse. They went on to say for those who disclosed their status, it was because they wanted some form of assistance, especially from the home-based care

programme. Some found it easier to disclose when they became very ill, when they got to a point where they realised they had nothing to lose.

Nevertheless, in the public domain discrimination was not evident. Observations by the researcher did not reveal any discrimination in the public. People were sharing beer with people suspected to be HIV positive. Things were however different in the home setting. Some families still separated the utensils they used for their PLHIV from the ones they used themselves. There were also different stages when a person was discriminated against. For instance, those who were positive but were still able to go about their productive activities were not discriminated against. The ones worst affected were those who got to the stage of being bedridden and could not help themselves with basic self care activities such as bathing or walking without aid.

It does not take a long time for a person to die when they get to the bedridden stage. This is usually because of lack of money for medical attention and the increasingly complex challenges of caring for the patient. Usually when a person gets to that stage they will need to access good medical services to address their more complex medical condition. The researcher witnessed a few people in this community who got to that stage and who, after anticipating their death, saw them somehow managing to get up to be on their feet once again.

The fight against stigma and discrimination was a community battle with all twenty one home-based care facilitators saying they had a large role to play. They went on to say community health care workers who taught against stigma and discrimination complemented their efforts. Responses from community members revealed that stigma and discrimination were largely due to lack of knowledge. With enough knowledge on how HIV and AIDS were spread and proper treatment of PLHIV, stigma and discrimination were highly reduced. Responses also indicated that churches also had a role to play in the fight against stigma and discrimination. According to 28 percent of responses, they had learnt from the church that the way they treated their PLHIV defined whether they discriminated or stigmatised their PLHIV. Churches, according to responses, advocated for proper care of PLHIV adding that there was no excuse for those suspected PLHIV to be discriminated against.

Stigma, according to responses, was reduced by several initiatives some of which are presented in Table 21 below. Please note that each of the percentages provided relates to the proportion of all the respondents in the sample who gave that specific response. As such, the percentages do not necessarily add to 100 percent.

Table 21: Factors that led to the reduction of stigma

Stigma and discrimination reduction reasons	Percentage %
Good knowledge on HIV and AIDS	48
Home based care	36
Christianity	34
Public awareness	30
Treating HIV and AIDS like any other disease	28
Wide spread help of PLHIV by Non governmental organizations	22
Disclosure by other community members	10

From the table above, it can be seen that a good knowledge of HIV and AIDS stood out as the most powerful factor in reducing stigma. The home-based care programme and Christianity were also powerful factors. However, disclosures appeared to be a particularly weak factor in combating stigma.

4.14 Summary

This Chapter presented data on the key findings regarding the extent to which Mutambi ward has attempted to cope with the impacts of HIV and AIDS. The main findings were that HIV and AIDS were among the key challenges that the Mutambi Ward community faced, and these strained their financial and other material resources, their productivity levels, and the human resources needed to provide the requisite home-based care services. The community, however, had developed ways of coping with these challenges, and chief among the coping strategies were Home Based care programme, dependence on Non governmental organisations for help, strengthening social support systems and altering traditional practices.

In this chapter, the researcher also focused on the respondents' views on the issues of stigma and discrimination and looked at the different dimensions in which HIV and

AIDS are looked at. One dimension of HIV and AIDS at the community level is the silence that surrounds the disease. The terror that people feel when confronted with HIV and AIDS contributes to a stigmatisation of HIV infected people that often extend to their families, usually the primary care givers. Nowhere is the rejection that accompanies stigma and discrimination more palpable than at the community level, among friends and neighbours at a time when support is most needed. In settings where information is scarce, treatment is nonexistent and care and support resources are marginal at best, it is easy to understand why HIV and AIDS prompt such a reaction. Widespread myths about the manner in which HIV is transmitted and the lack of comprehensive responsive services act as the engines of stigma and discrimination and drive misperceptions that those who are infected are somehow responsible for their sickness.

Also, looking at the results present on stigma, discrimination and disclosure, the findings show that the respondents viewed stigma as shame and discrimination as prejudice. Data collected from questionnaires and FGDs revealed that there was considerably more discrimination of PLHIV among the Vlei communities than among the non-Vlei communities. This is probably so because the Vlei members are a tight knit community who mostly come from the same village and therefore share common beliefs. Disclosure of one's HIV status was also not common, and seemed to be largely motivated by the need to access essential services such as food, drugs and medical care. People largely chose not to disclose because they feared to be stigmatised and discriminated against. Also, HIV was largely seen as a shameful disease, a disease for prostitutes and promiscuous people and most people did not want any of the two labels falling on them.

CHAPTER 5

COPING OR FAILING TO COPE: DISCUSSION OF RESULTS

5.1 Overview of results

In this chapter, an overview of findings of the impact of HIV and AIDS, and the outcomes of these impacts, on the ways in which Mutambi Ward community was coping is presented. These are summarized in Figure 5 below.

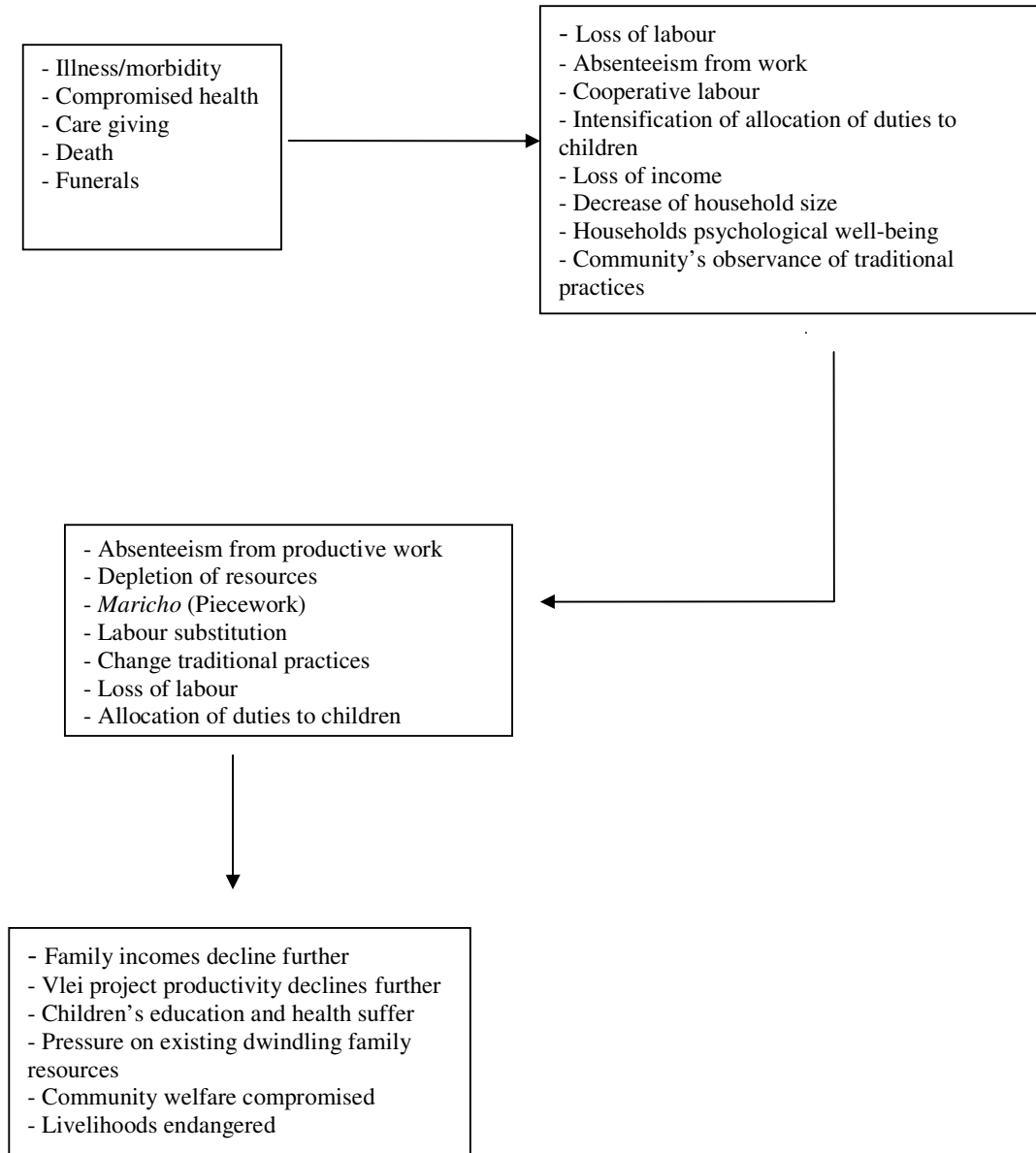


Figure 5: Impact of HIV and AIDS, outcome and resultant coping strategies

5.2 Impact of HIV and AIDS on household viability

Household viability refers to the ability of households to mobilize all the material and non- material resources, which enable it to function optimally and to meet the needs of its members (Mate, 2003). With the negative impact of HIV and AIDS on the labour force and on financial resources, many households experienced reduced viability. Vlei members were asked if their households were in any way affected by HIV and AIDS. Some 77.1 percent of the responses (N = 33) indicated that HIV and AIDS had affected them in one way or the other. Some of the impacts mentioned by these responses included: resources for agricultural inputs diverted to patient care (14.6%); failure by non infected members to go about their productive activities (2.1%); enormous productive time spent on care (12.5%); and reduction in work rate and death in the family (33.3%). As already mentioned, all these negatively impacted on the project activities. Productivity rates were lowered as a result of the fact that project members were diverting human and financial resources on nursing ill members of their families. This time is usually lost time because project activities only take place on Friday and when a Friday passes, project members have to wait for the next Friday. And when one looks at the nature of HIV and AIDS, (long illness in most cases), enormous time meant to be spent on Vlei activities as well as resources meant for the upkeep of households are lost. The impact of the long term debilitating illness on the household environment is to increase poverty levels. Overall, all these factors contribute to reducing household viability.

5.3 Household coping strategies

The impacts of HIV and AIDS are more devastating in small rural communities because of their fragile economies (Rugalema 2002:578). The household largely has been affected by these impacts of HIV and AIDS. The household has to manage these impacts on a daily basis. When a household fails to cope, it trickles down to the community level. Since the management of PLHIV requires human resources (people with the right skills and with the time), material resources that facilitate home-based care (such as gloves, food, bedding, soap and detergents), financial resources (e.g. for medication, transport, and the psychological will to act (motivation to look after the sick, and provision of emotional support), these households' ability to cope with the impacts is largely determined by their overall resource endowment. With more than

95 percent of households with PLHIV suspected to be HIV positive rated as poor, these households are already put in a situation of failure, or a struggle to cope.

5.4 Community coping strategies

Households, however, are part of the wider community, and their choice of action (or non-action) is to some extent influenced by the broader community framework. This framework consists of the community's livelihood (the economy and resources available within the community), its cultural values (what they feel is permissible or forbidden), social practices adopted by the community's members, the emotional or psychological disposition of the community's members (stress levels, provision of empathy, cohesion and support), and the patterns of power that govern members actions and behavior. The community's contribution is largely limited because of absence of resources. HIV and AIDS are one of the challenges the community are facing and results so far do not show major contributions that are being made by the community.

5.5 Home care

The majority of PLHIV in the home-based care programme are married people with some who have spouses that have passed away. This illustrates the way in which heterosexual transmission of HIV normally leads to serial deaths within families. In this case, as experienced in another study by (Nnko et al., 2000:587), those most at risk are not the single and unmarried or divorced but the 'safely' married.

5.6 Orphans

One of the most serious consequences of HIV and AIDS is the rapid increase in the number of orphans. By virtue of claiming adults in their prime years, it leaves orphans stranded, usually with very little resources. The increase of orphans is resulting in the great need to provide care and support on the social systems. At the family level, the extended family which has the traditional responsibility to care for orphans is under ever increasing pressures. Many grandparents are left to care for the young children. The elderly are shouldering parenting roles which they had assumed to be well past. During the study, it was established that there were limited child headed households in the study area. This was because the extended family took up the care for orphans. More than 50 percent of orphans are cared for by grandparents who in most instances

have no income of their own and have severe limitation on the number of orphans they can take on (National AIDS Council 2002 - Human Development Report 2003:84).

5.7 External support

Organisations and well wishers have been providing support to HIV and AIDS programmes in the community. Support has been coming in different ways including payment of fees for orphans, support for widows and funding of the home based care programme in the community. External support has been very essential in the community because the community has been fragile for a long time and has been hit by drought over a period of five years. Resources therefore have been very limited and dependence has largely been on outsiders. A combination of outsider effort and community effort is very essential as was seen to be happening in the home-based care programme. Resources by donors are then used at the local level by local people. These then provide the human resources who are known to the community.

5.8 Treatment

The majority of infected community members rely on the health sector for treatment. Already though, medical facilities have been negatively affected by HIV and AIDS and their ability to provide good quality health care services have largely been compromised. This has also been worsened by the fact that the majority of community members cannot afford the exorbitant fees charged by private doctors. They cannot even afford the hospital fees themselves and, for them, taking a patient to hospital is already a struggle. The ward has two local clinics that are only staffed by nurse aides and that hardly ever have any medication. This already has negative implications for the ill in the community and has to force them to go to the general hospital, further spending the very little resources that they may have. Coping with illness is therefore made difficult by such a situation.

5.9 Problem shared and not removed

The impacts of HIV and AIDS are affecting everyone. Coping by most households is by reliance on others. For example, households depend on relatives and neighbours to help them in light of labour. The community itself depends on NGO's and the government for intervention strategies to alleviate the challenges brought on by HIV

and AIDS. Households also rely on relatives for financial support. When there is a funeral, households share most of the funeral related costs and activities with those that surround them. The church helps those who have lost their loved ones by conducting memorial services. The community, households and the home-based care programme all rely on external support to help them take better care of their PLHIV. All these are pointing to one thing. The burdens brought about by HIV and AIDS have been adverse to households and have not been completely catered for. Households that are getting help and those that are helping are merely sharing the burden and not removing it.

Agriculture and food security

Agriculture and food security are compromised by the presence of HIV and AIDS. The chronic illnesses that accompany the deterioration of the immune system deplete household assets, reduce labour and lead to reduced crop production. Care givers' productive working hours are reduced as they divert time away from income earning activities to care for the ill household members. HIV and AIDS affected households also experience a reduction in the quality of labour. Research results show the enormous productive time that is used for HIV and AIDS related activities. In the long term, this is having a negative impact on agricultural production with households being forced to neglect agricultural activities and to prioritise caring roles.

In Zimbabwe, one survey found that agricultural output declined by nearly 50 percent among households affected by HIV and AIDS as compared to those not affected by HIV and AIDS, (FAO 2002:96). Frequent funeral attendance also affected land use and agricultural productivity. This has further exacerbated the problems brought about by HIV and AIDS because maintaining a strong immune system for those who are positive then becomes difficult. Hunger worsens the situation.

Funerals

Funerals have become a very common event in rural societies particularly where, according to prevailing custom, even those adults who die in town are normally ferried to their rural homes for burial. In the community in question, people do not work when a Vlei member, any member of the family and a community member, or even those who are ferried from town who might not be in the project or in anyway

linked to the project dies. This means that any burial in the community that falls on a Friday results in absenteeism from work by Vlei project members. The broad ridge and broad furrow project as observed on several fieldtrips was locked and nobody worked on it whenever there was a funeral in the community. This does not only apply on this project, it is more of an African 'funeral wake' concept where tradition expects, but does not demand, mourners to gather and attend to burial when a person dies. In such a case, for instance, Vlei members cannot even send replacements, or their children to work on their behalf because the area in question restricts people from undertaking any productive work when there is a funeral in the community. Studies carried out in Zimbabwe have revealed a reduction in agricultural output as a result of HIV and AIDS. The (Zimbabwe Farmers Union - ZFU 2000:94) reported a 50 percent reduction in agricultural production. This was because the workforce was affected by illness, death, absence due to illness and attending funerals. The loss of human life and productivity due to this disease is a major threat to socio-economic development.

The results indicated that more than thirty funerals had directly affected the Vlei irrigation project during the period of this study. These are frightening figures that are most likely to soar especially when one looks at the average number of suspected PLHIV in the home- based care programme of Mutambi Ward (on average 67 each month) without even considering those who are not in the programme and those who are in town who later come for burial after death.

(Gomo et al., 2003:94) highlighted the impacts of HIV and AIDS on the agricultural sector in Zimbabwe. Agriculture is the backbone of the Zimbabwean economy. Its mandate is to provide food security for all Zimbabweans. Thus, the negative impact of HIV and AIDS on the sector is of great concern. Evidence is accumulating that HIV and AIDS is affecting both commercial and subsistence agricultural output in Zimbabwe. A study in the Lowveld Sugar Estates in 1996 showed an HIV prevalence of over 30 percent among sugar cane cutters, with an incidence of 6 percent per annum (Gomo et al., 1996:94, unpublished). HIV and AIDS have a serious impact on the workforce as it is affected by illness, death, absence due to illness and attending funerals. Kwaramba, (1997:94) and Zimbabwe Farmers Union (2000:94) reported a 50 percent reduction in smallholder production. Reduction in crop output was shown

by the following statistics: maize 61 percent reduction in output, cotton 47 percent reduction in output, vegetables 49 percent reduction in output, groundnuts 37 percent reduction and cattle owned 29 percent reduction in output (Kwaramba, 1997: 94).

Furthermore, a study conducted by (Mutangadura, 1999:95) reported that in the 1997/98 season, agricultural extension workers in Gweru district lost on average 10 percent of their salaries as a result of attending funerals. Thus, HIV and AIDS pose a serious threat not only to nutrition, but also to food security in general. When a family has an AIDS patient, the average household income falls by a range of 52 to 67 percent and health costs quadruple (Jackson, 2000: 98). Smallholder agriculture impact studies revealed a decline in cultivated acreage for the year 1997/98 due to reasons related to HIV and AIDS, shortage of labour, lack of essential resources, draught power and farm implements. AIDS affected households showed poor crop management and harvest, experienced loss in marketed output of more than 50 percent of maize, cotton, and sunflowers (Kwaramba, 1997:94). The loss of husbands, who are often responsible for marketing, led to marked declines in revenue.

A study conducted by the (FAO in March 2003:94) revealed that, of the 193 farmers interviewed, 70 percent indicated that HIV and AIDS had severely reduced their farming activities, whilst 50 percent claimed that both crop and livestock production had been severely affected by the impact of the disease in the last three years.

The prevalence rates of HIV are so high and their linkages with food security have become obvious and (De Waal, 2002: 96) argues that this food insecurity can be termed the 'new variant famine' which requires whole new approaches towards understanding food security in the context of the HIV and AIDS pandemic. Research has shown that HIV and AIDS accentuate the fragility of livelihood systems. HIV and AIDS have direct and negative effects on household exchange entitlements by decreasing the quantity, the quality, and stability in income earning activities resulting in increased per capita income (SADC-FANR VAC, 2003). With regards to quality and quantity of labour, HIV and AIDS affected households have less working members in relation to non-working members. Projected loss of agricultural labour force as a result of HIV and AIDS by country shows the following reductions: Namibia - 26 percent, Botswana - 23 percent, Mozambique - 20 percent, South Africa

- 20 percent, Kenya - 17 percent, and Malawi - 14 percent. HIV and AIDS affected households experience a reduction in quality of labour. They end up relying on children and the elderly for the greater proportion of their income despite the fact that children and the elderly may not have as many casual labour opportunities in competitive labour markets as able-bodied adults.

5.10 Coping with labour demands

The responses on how the Vlei community is coping with labour give insight on how labour is being managed in the real life context. Whether there is dedication from this kind of labour though is a different issue. Cheap and convenient labour is the resultant factor when one has to be rendering the care-giving role. The quality of labour provided by relatives, replacement and even by children is very much questionable. When relatives provide labour at the expense of their own welfare, the burden is merely shared not removed. When children participate in labour, whose demands exceed their physical, social and psychological capacity and to the detriment of their education and health, this becomes child abuse, child exploitation, and child labour. Effectively, this denies them their rights as children (UNICEF 1990:6).

5.11 Illness

Taking care of a person with HIV or AIDS related illnesses is not only an emotional strain for household members, but also a major strain on household resources. Loss of income, additional care-related expenses, reduced ability of caregivers to work, mounting medical fees and funeral expenses are pushing affected households of the project deeper into poverty. Productivity and crop production is definitely affected by illness, or absence due to illness, given this scenario. Food security in this instance is also affected.

When a family member has HIV and AIDS, labour shortage becomes a central issue as members of the family need labour in order to cope and yet they get occupied with HIV and AIDS related caring activities. HIV and AIDS affect mostly the productive age group of 15-49 years. In households with a family member with either HIV or AIDS, this means two people fail to attend to productive activities at any given time. This is the sick person and the caregiver. AIDS often strikes more than once within a family given its heterosexual transmission. Bearing this in mind the care-giving role is

becoming an activity that households alone cannot cope with and communities have to provide additional support. This has major negative long-term effects not only on the households, but also on the community as a whole.

Some 67.3 percent of the Vlei project members admitted to having HIV and AIDS related deaths at the household level, and only 33.3 percent contended they had not. These statistics help to illustrate the number of people who had to deal with HIV and AIDS related illness or death at one time or the other. Frequent funerals reduce labour input and associated responsibilities for the Vlei members. Death also results in expenses, absenteeism from work and reduction in labour force. Death even affects other members of the project who are not directly affected because they are forced by community traditional law not to work. Numerous hours of productive work are lost. At this rate, the project has major challenges ahead of it in coping with HIV and AIDS related impacts and how they affect their work in the broad ridge and broad furrow project. Although the community has developed coping strategies, the other question to ask is how far these coping strategies are helping the community to cope. The very fact that HIV and AIDS infects the productive age (15-49 years) who are generally the strong, and leaves behind the weak undermines the capacity of the project to cope especially in the long term. Finally, one should pose the question are these coping strategies effective enough to cushion the project from the impacts of HIV and AIDS and its related activities?

CHAPTER 6

6.1 Conclusion of the study

The term coping strategies is a term with value in explaining household experiences and responses to HIV and AIDS. Indeed, the community has responded to the impacts of HIV and AIDS in different ways. Reproductive and productive activities in Mutambi Ward are being adversely affected by the impacts of HIV and AIDS. HIV and AIDS result in illnesses/morbidity, death, absenteeism due to illness and absenteeism due to death and these are serious contributing factors that prevent farmers and the community at large from going about the productive activities. All these result in family's inability to meet labour requirements, compromise households psychological well being and communities' observance of traditional practices such as funerals and mourning practices. Effectiveness of coping strategies is another big question to the study. Effectiveness of coping strategies is noted in the short term and not in the long term. As the pandemic progresses and keeps weakening structures already in place in the community, more stronger and more rigid coping strategies will have to be put in place by the community for them to cope more easily with the impacts of HIV and AIDS.

The Zungwi Vlei crop production project is specifically designed to enhance household viability through the generation of additional resources. Since HIV and AIDS diminish households' ability to meet the labour requirements on which the crop production project depends, it effectively has dealt a devastating blow on the Zungwi Vlei project. As is typical of a syndrome of this nature, the very mechanisms designed to safeguard livelihoods are the objects of attack, resulting in weakened coping systems. Household viability has an overall effect on the crop production project. Bearing all this in mind, it can therefore be seen that HIV and AIDS affected households have poor crop management and harvests as they have other HIV and AIDS related activities they have to attend to. In the end, household viability impacts immensely on the overall output of the crop production project, thus further diminishing their resource base and weakening their ability to cope. In Mutambi wards, the impacts of HIV and AIDS have put some households in a position of failure to cope. When a household is forced to sell assets to raise money for caring activities, is this coping or failing to cope? This is a forced decision as a result of no

other solution. The extent to which households are coping and effectiveness of responses in the short and long term is highly debatable. The idea of coping should therefore be rethought.

6.2 Major findings

The impacts of HIV and AIDS on Mutambi Ward are varied. HIV and AIDS home care is diminishing the ability of households to meet labour requirements for crop production and thereby compromising agricultural productivity. The study showed that due to failure of households to cope with care-giving roles, communities had to provide additional support resulting in major long-term impacts both at household and community level. Mechanisms meant to safeguard livelihoods are the objects of attack, resulting in weakened coping systems. When relatives provided labour at the expense of their own welfare, the burden was merely alleviated through sharing, but the burden remained intact, thus making it more of a palliative than a coping response. The quality of labour provided by external support has to a limited extent alleviated the burden of labour. This has also led children to participate in labour, whose demands in some cases exceeded their physical, social and psychological capacity.

Loss of income, additional care-related expenses, reduced ability of caregivers to work, mounting medical fees and funeral expenses pushed affected households into deeper financial problems and into poverty. This ultimately affected productivity in Mutambi Ward resulting in poor food security. Generation of additional resources was compromised, resulting in a diminished resource base. The battle of HIV and AIDS was therefore lost as the community was struggling to cope.

6.3 Recommendations

It is this study's humble submission that findings from this study can be used in policy formulation and intervention programmes, particularly those aimed at providing assistance to affected households. Findings from this study show to a great extent how much providing the care role is negatively impacting on productive activities that are a source of livelihood for community members. Even though there are few support systems in the community such as the Home-based care programme, its efforts are being undermined by the absence of resources. This study therefore recommends the following:

- a. Providing resources for community support systems such as the home-based care programme by NGO's and the government. These resources will directly benefit those affected by HIV and will also contribute towards any community projects targeted for HIV and AIDS affected households. This would boost and improve effectiveness and efficiency in caring roles.
- b. Strengthening household support systems by introducing projects that help households mobilize resources. These resources will make provisions of resources that will enable them to provide quality care that improves the quality of life for those infected by HIV and AIDS. Such projects enhance household financial resources allowing quality care (good medical attention, provision of a well balanced diet) to be provided to the affected.
- c. Information dissemination in Mutambi Ward by Agricultural extension officers that promotes the growing of less labour intensive crops such as cassava and sweet potatoes. These labour intensive crops equally nutritious will reduce the amount of time people have to spend in the field giving them more time for caring roles. This will ensure people have food for consumption and also time for caring roles.
- d. The other main challenge is providing treatment and care to those living with HIV in Africa, in particular ARVs, which can allow people living with HIV to live longer and healthier lives. NGO's working in food distributions should also strive to provide assistance to PLHIV in providing them with food handouts so that they get a nutritionally complete diet helping them live positively with HIV. Many African countries have made significant progress in their treatment programmes in recent years (notably Uganda) and it is likely that the next few years will see many more people receiving the drugs. However, in some cases ARV drugs are given to PLHIV who have no food and these drugs do more harm than good in such people.

- e. Tackling the AIDS crisis in Africa should become a long term task for governments and sustained effort should be placed in planning within African countries and the international community. Key in such discussions is the way forward in avoiding new infections looking at what has been working. Efforts by all governments should be placed on intervention projects such as Prevention of Mother to Child Transmission of HIV (PMTCT). Such programmes promote an HIV free generation.
- f. Introduction of training to family care givers on caring for HIV or AIDS patients should be done at a national level. These trainings supported by NGO should be provided at the grassroots' level. Many of those with HIV end up in their rural homes when their health deteriorates where they are looked after by grandparents or parents who often do not have knowledge n how to provide the right care to a person living with HIV or AIDS. This will limit the pressure on community home based care workers who to some extent may prioritise their own productive activities. This will also ensure there is a trained person always present with the HIV or AIDS client.
- g. Lastly there is need for strong collaboration between the Government of Zimbabwe and NGOs operating in Mutambi Ward in order to enhance the quantity and quality of support to households and the community who are struggling with the impacts of HIV and AIDS.

BIBLIOGRAPHY

- Baylies, C. (2000). *HIV/AIDS in Africa: Global and local inequalities and responsibilities*. Review of African Political Economy (ROAPE). 2000.
- Chiduo, B. (2000). Tanzania AIDS care: Learning from experience. Dar es Salaam.
- Deacon, H. (2005). Understanding HIV and AIDS Stigma. Human Sciences Research Council and Harriet Deacon.
- De Waal (2002). Zimbabwe Human Development Report 2003. Harare.
- Economic Commission for Africa, (2006). Mitigating the impact of HIV/AIDS on smallholder agriculture, food security and rural livelihoods in Southern Africa: Challenges and action plan.
- Exnevia Gomo et al. (2005). Household survey of HIV prevalence and behaviour in Chimanimani District, Zimbabwe.
- FAO (2003). Zimbabwe Human Development Report 2003. Harare.
- Jackson, H. (2002). AIDS Africa, Continent in Crisis. SAFAIDS.
- Kwaramba, A. (1997). Zimbabwe Human Development Report 2003. Harare.
- Mate, R. (2002). *Impact of HIV and AIDS on household viability*. Zimbabwe Human Development Report 2003, 85-87. Harare.
- Mutangadura, (1999). Zimbabwe Human Development Report 2003. Harare.
- Rugalema, G. (2000). *Coping or struggling? A journey into the impact of HIV and AIDS in Southern Africa*. 537-546, Review of African political economy ROAPE No. 86 2000.
- SADC-FANR VAC (2003). Zimbabwe Human Development Report 2003. Harare.
- SAFAIDS (2002). HIV/AIDS Action: Responding to Stigma and Discrimination: 53, Harare.
- Tumushabe, J. (2005). The impacts of HIV and AIDS on Rural Livelihoods in Southern Africa. Harare, Zimbabwe.
- United Nations Joint Programme on HIV/AIDS (UNAIDS) Report, 2004.
- United Nations Joint Programme on HIV/AIDS (UNAIDS) Report, 2003.
- UNICEF (1990). First Call for Children: Convention on the Rights of the Child (CLC). New York: UNICEF.

Wilson, F. (2000). Tanzania AIDS care: Learning from experience. Tanzania.

Zimbabwe Farmers' Union (ZFU) (2000). Zimbabwe Human Development Report 2003. Harare.

<http://www.avert.org/aids-zimbabwe.htm> [Date(s) accessed: 10.04.06, 12.07.06, 23.06.05, 02.08.06]

<http://ijsa.rsmjournals.com/cgi/content/abstract/17/6/360> [Date accessed: 08.02.2007]

http://www.uneca.org/eca_resources/major_eca_websites/icpd/fourth/fc4-
[Date accessed: 23.03.04]

<http://www.unaids/bangkok#> [Date accessed: 08.02.07]

http://www.abtassociates.com/presentations/Tania_Dmytraczenko_final [Date accessed: 08.02.2007]

<http://www.avert.org/worldstats.htm> [Date accessed: 11.02.2007]

http://farmradio.org/english/radio-scripts/73-1script_en.asp [Date accessed 17.01.06]

<http://www.avert.org/hiv-aids-africa.htm> [Date accessed 27.10.09]

http://www.kff.org/hivaids/upload/3030_9.pdf 16.10.09. [Date accessed 27.10.09]

<http://hivinsite.ucsf.edu/global?page=cr09-zi-00> [Date accessed 14.10.09]

<http://www.thefreedictionary.com/stigma> 24.10.09

<http://www.avert.org/worldstats.htm> 16.02.06

<http://www.avert.org/safricastats.htm> [Date accessed 25.10.09]

<http://medical.bizcommunity.com/Article/196/149/40223.html> [Date accessed 14.10.09]

http://www.searo.who.int/LinkFiles/Training_Materials_voluntary-module2-.pdf [Date accessed 23.09.09]

<http://aidsaction.info/cwc/section4.html> [Date accessed 26.07.09]

ANNEXES

ANNEX 1: Interview Schedule for Vlei Community Members

Name of interviewer

Date of interview .
.....

Name

Household ID

Village

1. How has HIV and AIDS affected you at household level?

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2. Do you have any relatives or children that have died due to HIV and AIDS or suspected HIV and AIDS?

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3. Do you have relatives or children who are ill or sick due to HIV and AIDS related illnesses?

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4. What coping strategies have you adopted as a result of HIV and AIDS in your daily lives?

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5. How have you been coping with labour in light of the epidemic?

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6. Are your (productive and household) activities getting affected by you visiting sick relatives or community members and attending funerals in the community?

☐ Yes

☐ No

If yes, how?

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.....
.....
.....

7. Is the home-based care programme in anyway helping you to cope with HIV and AIDS?

☐ Yes

☐ No

If yes, how?

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8. How do you cope with the loss of other community members?

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ANNEX 2: Mutambi Ward Interview Schedule on Disclosure.

Name of interviewer

Date of interview

Name

Sex

Age

1. Are there any community members who are disclosing their HIV and AIDS status?

Yes ☐

No ☐

2. If yes, to whom do they disclose their status to?

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.....
.....
.....

3. Why do they disclose?

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.....
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.....

4. If no, why do you think people do not feel free to disclose their status

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5. Would you disclose your HIV status?

Yes ☐

No ☐

Give reasons for your answer.....

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6. What is your understanding of the word stigma in relation to HIV and AIDS?

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7. What is your understanding of the word discrimination in relation to HIV and AIDS?

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ANNEX 3: Mutambi Ward Interview Schedule on Coping with the Impacts of HIV and AIDS

Name of Interviewer

Date of Interview

Name

Village

1. In view of HIV and AIDS, how is your household coping with the impacts of HIV and AIDS?

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2. Do you have relatives who are suspected to have died from HIV and AIDS?

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3. What is your church doing to help you cope with the impacts of HIV and AIDS?

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4. How has the home based care programme helped you as a household cope with the impacts of HIV and AIDS?

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5. How is the community coping with loss?

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6. If any, in what way has the emergence of HIV and AIDS changed your way of life?

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ANNEX 4: Mutambi Ward FGD Guideline Questions on Livelihoods

Community Members

1. What are your main sources of income?
2. Have these been affected in any way by the impacts of HIV and AIDS?
3. What are your main uses of income?
4. Has there been a change to the input you give to agricultural activities? i.e. specify on gender, resources, time and labour).
5. If yes, what do you attribute this change to?

ANNEX 5: FGD Guideline questions on NGO support for Home Based Care Workers

1. Which organisations have you been working with in HIV and AIDS related activities?
2. What have these organisations been doing to help?
3. Can you rank the organisations according to the contribution they have made?
4. Are these organisations making significant contribution in helping the HIV and AIDS situation in the community? If yes, why do you say so? If no why do you say so?

ANNEX 6: FGD Guideline Questions on Coping with the impacts of HIV and AIDS

1. To what extent do households cope with the impacts of HIV and AIDS?
2. Are there resources available in households/community to combat and cope with the impacts of HIV and AIDS?
3. How do you think affected households are coping on a day-to-day basis?
4. Do you think Mutambi Ward has enough human resources (particularly people with the right skills and time), material resources and financial resources to be running home based care programmes?
5. Is there anything that individual households are doing to contribute to the wider community in relation to coping the impacts of HIV and AIDS?
6. Would you say there is action or non action from individual households and the community in contributing to helping each other cope with HIV and AIDS impacts?
7. Besides community health care workers, are there any other community members who are getting educated on the best and proper ways of taking care of PLHIV?

ANNEX 7: Health Challenges

Disease	Occurrence	Gender	Preventive Measure	Health seeking behaviour

ANNEX 8: Guideline Questions with the Home Based Care Facilitator

1. How has the HBCP been helping its beneficiaries?
2. Have families been able to provide a balanced diet for PLHIV?
3. Do you think the programme has made meaningful a meaningful contribution to the community?
4. Do families try to make resources available?
5. Are family care givers patient with the ill?
6. What mode of treatment do most PLHIV opt for?
7. At what stage do most people go to the hospital?
8. At what stage is support for patient necessary?

ANNEX 9: Interview Guideline Questions with Church Representatives

1. In what ways have the community been affected by the impacts of HIV and AIDS?
2. Has the church been directly affected?
3. What is your church doing to help the situation?
4. Is there any organisation that is helping you with your HIV and AIDS activities?
5. Are there particular individuals the church is helping?
6. The impacts of HIV and AIDS in this ward are enormous, what would you attribute this to?
7. Has there been a change in behaviour amongst the youth?

ANNEX 10: Interview Guideline Questions with Mutambi Ward Clinic Nurse

1. How much has the clinic been doing to help those who come to seek for treatment?
2. Has the clinic been able to provide medication to all those who have been coming to seek for treatment?
3. From the diagnosis you have been making of those who came to seek for treatment, what ailments were you meeting?
4. How many people visit the clinic on a daily basis (average number to be captured)?
5. How can you describe the people who come to the clinic (can they afford hospital fees in Zvishavane and can they afford to buy medication prescribed to them)
6. Can you describe the number of women and the number of men who come to the clinic?
7. What age group frequents the clinic the most?
8. Are children coming to the clinic? If yes what do you mainly treat them for?

ANNEX 11: Interview Guideline Questions with the Ward Councillor

1. As a Councillor, what is your contribution to the community in fighting the HIV and AIDS epidemic?
2. What is your view of the Home based care programme?
3. What would you say is being done by churches?
4. Your view on traditional healers?
5. As a Vlei member, would you say HIV and AIDS are affecting Vlei activities?
If yes, in what ways?
6. What is the Government's role in all this?
7. What is being done by Mutambi Community in the fight against HIV and AIDS?
8. What challenges do you face in your HIV and AIDS activities?

ANNEX 12: Interview Guideline Questions with Traditional Healers

1. How long have you been a traditional healer?
2. What are some of the diseases that you come across on a day to day basis?
3. How do you treat most of these diseases?
4. Do you ever refer PLHIV to Medical institutions?
5. Is there any protective clothing that you use during the execution of your duties?
6. Are there any organisations that you are working with?
7. On average, how many PLHIV do you treat in a week?
8. What is the sex ratio of the PLHIV that visit you?
9. How much do you charge for your services?
10. What is the age range of your PLHIV?

ANNEX 13: Monthly Death Register

Name of village	Sex	Age	Death date	Burial date

ANNEX 14: Home Based Care Register

Number of PLHIV visited from <u>2003</u>			
MONTH	MALE	FEMALE	DECEASED
July			
August			
September			
October			
November			
December			
Number of PLHIV visited <u>2004</u>			
January			
February			
March			
April			
May			
June			
July			
August			
September			
October			
November			
December			
Number of PLHIV visited <u>2005</u>			
January			
February			
March			
April			
May			
June			
July			
August			
September			
October			
November			
December			
Number of PLHIV visited <u>2006</u>			
January			
February			
March			
April			
May			
June			

ANNEX 15: Home Based Care Register

Name of Caregiver

Sex

Age

Name of patient	Sex	Date of Birth	Marital Status	Illness duration	Economic Status	Symptoms of Disease

Name of patient	Sex	Date of Birth	Marital Status	Illness duration	Economic status	Symptoms of Disease

Name of patient	Sex	Date of Birth	Marital Status	Illness duration	Economic Status	Symptoms of disease

ANNEX 16: Zungwi Vlei Diary

Date	Time Taken	Activities	Observations	No of Vlei members	Comments