

**ADULT MORTALITY TRENDS SINCE THE INTRODUCTION OF FREE
ANTI RETROVIRAL THERAPY IN A RURAL HOSPITAL IN UGANDA**

by

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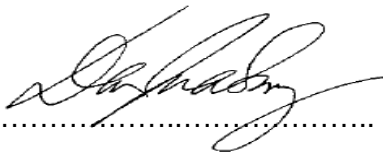
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DECLARATION

I declare that **ADULT MORTALITY TRENDS SINCE THE INTRODUCTION OF FREE ANTI RETROVIRAL THERAPY IN A RURAL HOSPITAL IN UGANDA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



.....
SIGNATURE

(David Mabirizi)



.....
DATE

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ADULT MORTALITY TRENDS SINCE THE INTRODUCTION OF FREE ANTI RETROVIRAL THERAPY IN A RURAL HOSPITAL IN UGANDA

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ABSTRACT

Uganda has experienced 1.6 million deaths due to HIV/AIDS related illnesses. Introduction of free-ART in rural hospitals that bear the burden of AIDS reduces adult morbidity and mortality. The study design was a quantitative, retrospective and descriptive design through data mining of medical records.

In the six years, hospital admissions decreased by 16.7% and the median age at death increased by seven years. Hospital mortality increased from three to seven deaths per 100 admissions per month. Male to female mortality was 1:1.6 and females in the 15-34 age group had a 37% higher likeliness of dying in hospital compared to males. Deaths from sub-counties with an ART site reduced by 4% to 8.6%. The data revealed that despite ART coverage of 60%, mortality rates showed a rising trend. Free access to ART's over three years did not make any observable changes to overall mortality.

Therefore, ART access contributed to a decline in overall hospital admissions, an increase in median age at time of death and a reduction in deaths from sub-counties with an ART site. There was no reduction in overall hospital mortality rate.

Key terms: Adult, Antiretroviral treatment (ART), HIV/AIDS, hospital, Mawokota South health sub-district, Mortality, Morbidity, Mpigi district, Uganda

Decidation

This work is dedicated to the health workers in the Mpigi District who devote their commitment, time and energy to taking care of the sick especially People Living with HIV/AIDS.

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The work you all do is appreciated and may the Lord reward you abundantly.

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List of abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral treatment
ARV/ARVs	Antiretroviral /Antiretrovirals
CD4	Cluster Differential 4
CDC	Centres for Disease Control and Prevention
CDR	Crude Death Rate
CI	Confidence Interval
CIA	Central Intelligence Agency
DNA	Deoxyribonucleic Acid
GTATM	Global Fund for AIDS, TB and Malaria
HAART	Highly active antiretroviral treatment
HCT	HIV Testing and Counselling
HIV	Human Immunodeficiency Virus
MDGs	Millennium Development Goals
OGAC	Office of the Global AIDS Coordinator
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PLWHA	People Living with HIV/AIDS
PMR	Proportional Mortality Ratio
RNA	Ribonucleic Acid
STD/STI	Sexually Transmitted Disease/ Sexually Transmitted Infection
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations International Children's Education Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1

Orientation to the Study

1.1 INTRODUCTION

One of the key objectives of any well-functioning health care delivery system is to maximise the prevention of disease and to reduce or contain the incidence of disease and the rates of mortality. A careful monitoring of the prevalence of morbidity and rates of mortality is, therefore, a vital function of any effective health service delivery system. In this study, the researcher has undertaken an audit and analysis of adult mortality trends both before and after the introduction of free anti-retroviral therapy (ARV) in a rural hospital setting in Uganda.

The researcher deliberately chose a rural setting in Uganda as the focus of this study because, in a previous study undertaken in Masaka, a rural district in Uganda, where the number of HIV-infected people was calculated to be 8% of the total number of people in the district, 41% of all adult deaths were attributed to HIV infection and its subsequent complications and progression towards full-blown AIDS (Lopman, Barnabas, Hallet, Nyamukapa, Mundandi, Mushati, Garnett & Gregson 2006:189; Nunn, Mulder, Kamali, Samarti, Chiesi, Geraci, Andreoni & Vella 1997:[1]). Increases in the overall morbidity and mortality rates in Uganda during the past three decades have therefore been associated with the very large number of people in the general population who have been infected by the human immunodeficiency virus (HIV) and who died from opportunistic infections and other complications that are associated with the acquired immunodeficiency syndrome (AIDS).

While Ugandans have had free access to antiretroviral treatment (ART) for the past four years, the monitoring of mortality trends in rural hospitals has either been inadequately undertaken or non-existent.

The researcher undertook this study in order to answer important questions such as:

- What was the incidence of adult hospital mortality before free ART became available to the general population in Uganda?
- What was the incidence of adult hospital mortality after free ART had become available to the general HIV-infected population?
- Was there any statistically significant correlation between factors such as gender and the age of patients among those groups who experienced the highest mortality rates?

Other important questions that the researcher took into consideration before arriving at his conclusions were the following:

- Were there any other significant factors that needed to be taken into consideration because they correlated significantly with the hospital mortality rates in this rural setting in Uganda?
- What conclusions should one reach about the overall effect of free ART on hospital mortality rates in the selected rural hospital in Uganda?

There are two main reasons why the answers to these questions were chosen by the researcher as the focus of this study. Firstly, such questions are the key questions that every district management team, hospital manager and health unit management team in high HIV-prevalence settings should be asking themselves on a quarterly and annual basis. Secondly, the findings and recommendations of this study became the basis for implementing targeted interventions that were designed to reduce mortality rates. These answers serve as benchmarks for comparison and future research in comparable situations and contexts.

The researcher sought the answers to these questions by reviewing the history and trends that have been evident in the global HIV/AIDS epidemic, and by focusing his attention on sub-Saharan Africa and Uganda in particular because it is one of the countries that has been most affected by this virus.

In the first part of the study, the researcher retrospectively reviewed all adult admissions and deaths in a rural hospital between July 2002 and June 2008 in order to determine

mortality trends and those related demographic aspects of mortality that were identifiable from the hospital's records. The data thus accumulated for the specified period (between July 2002 and June 2008) was arranged in two sets that reflected the age of patients at the time of death, the gender of deceased patients, and the reported causes of death (where these had been indicated in the hospital's record). These two sets of data (one from the era before free ART had been available and one from the period in which free ART was available to patients), were then compared and analysed.

1.1.1 The human immunodeficiency virus epidemic in perspective

The Human Immunodeficiency Virus is largely spread by means of unprotected sexual intercourse (sexual intercourse without the use of condoms) between an infected person and an uninfected person. Once an individual is infected with the HIV, he or she, if left untreated, eventually begins to manifest the syndrome called AIDS (the Acquired Immunodeficiency Syndrome). The HIV was first identified in 1981 in the United States of America (USA) among men who had been engaging in anal sexual intercourse with other men (Centres for Disease Control and Prevention (CDC) 1998:[1]; Hall, Geduld, Boulos, Rhodes, An, Mastro, Janssen & Archibald 2009:S13). Ever since the identification of the HIV, an increasing number of men and women throughout the world have become infected with the virus and have eventually succumbed to one or another of the opportunistic infections and conditions that accompany AIDS and that invariably result in the death of the patient (Hall et al. 2009:S13). What was thus originally called “the gay plague” because it seemed to affect only sexually active homosexual men, is now known to be a virus that affects all men and women who engage in unprotected sex – regardless sexual orientation or preferences.

In over 75% of cases that have been positively identified throughout the world, the virus has been transmitted by means of heterosexual contact in which either blood or other bodily fluids have been exchanged between partners. These infections have resulted in a spectacular increase in various kinds of morbidity and mortality in all affected countries throughout the world – but especially in the countries of sub-Saharan Africa. This overwhelming predominance of HIV infections is indicated in figure 1.1 below (Joint United Nations Programme on HIV/AIDS [UNAIDS] & WHO 2007:3). The factors that have made the countries of sub-Saharan Africa especially vulnerable to the impact of the HIV and AIDS, are discussed in the following chapter (chapter 2).

1.1.2 The global human immunodeficiency virus disease situation

Figure 1.1 (below) shows that sub-Saharan Africa is the region globally that is most severely affected by the HIV/AIDS epidemic. The number of people who are infected in this region is far out of proportion to the total number of people who live in it. Sub-Saharan Africa accounts for 22.5 million people who are living with HIV/AIDS (PLWHA is often used as a working acronym for “people living with HIV AIDS”). This extraordinary number should be compared with a number of infections in the North America (estimated at 1.3 million), Eastern Europe and Central Asia (1.6 million), South and South-East Asia (800 000), the Middle East and North Africa (380 000), and Western and Central Europe (with 760 000 HIV-infected people in this region) (UNAIDS & WHO 2007:39). Sub-Saharan Africa is therefore the most affected region of the world with more than two thirds of the HIV burden in the world.

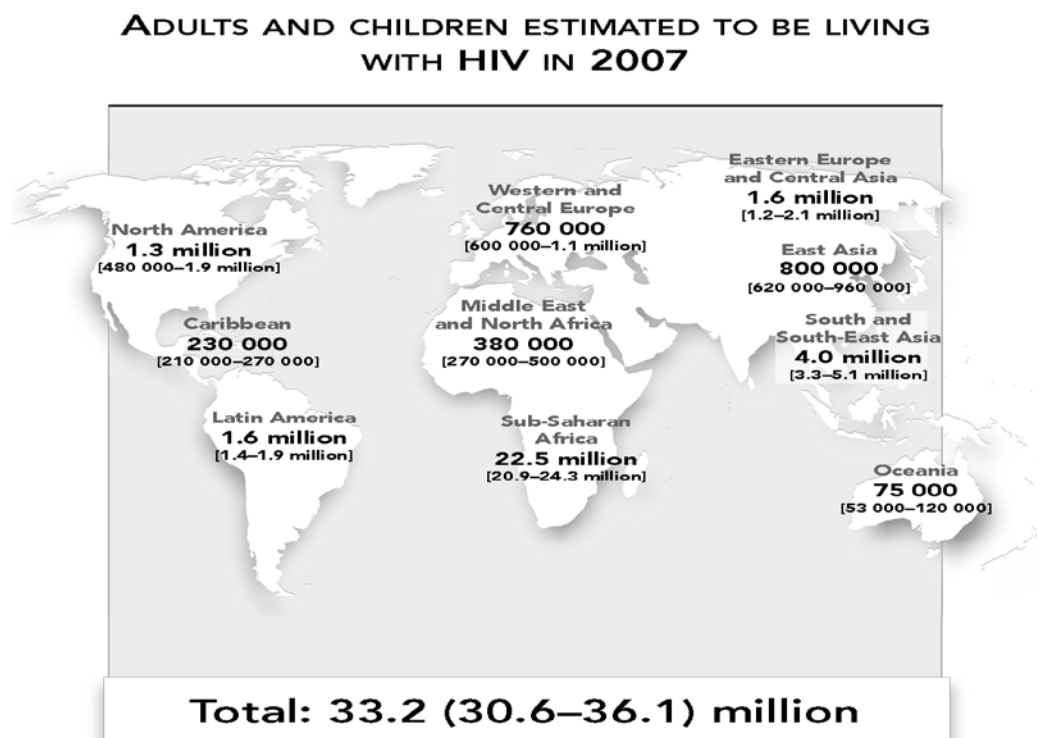


Figure 1.1: The estimated number people living with HIV worldwide (2007)

(Source: UNAIDS & WHO 2007:39)

Although HIV was regarded in 2007 as the most serious infectious disease in the world (UNAIDS & WHO 2007:4), a review of global prevalence trends shows that there were localized reductions in the prevalence of HIV infection in some countries. This reduction

in prevalence was associated with a reduction in HIV-related deaths. This reduction can be partly attributed to the increasing number of people who have free access to ART and partly to a 53% decrease in the number of new HIV infections (Fang, Hsu, Twu, Chen, Chang, Hwang, Wang, Chuang & The Division of AIDS and STD 2004:883; UNAIDS & WHO 2007:4).

In East Africa, the prevalence of HIV reduced from 12.9% (7.0–16.9%) in 1997/98 to 8.5% (5.3–14.0%) in 2002. Uganda (the country that is the focus of this study), reported a “rapid decline in prevalence during the mid and late 1990s” (Asamoah-Odei, Garcia-Calleja & Boerma 2004:38); likewise, in Kenya, HIV infections fell from 13.6% (12.2–27.1%) in 1997/98 to 9.4% (6.6–14.3%) in 2002 (Asamoah-Odei et al. 2004:38)

A closer examination of global and regional trends showed that HIV infections were distributed in two different patterns: (1) a generalized epidemic pattern of distribution in sub-Saharan Africa, and (2) a concentrated epidemic pattern of distribution in the rest of the world (Halperin & Epstein 2004:4; UNAIDS & WHO 2007:4).

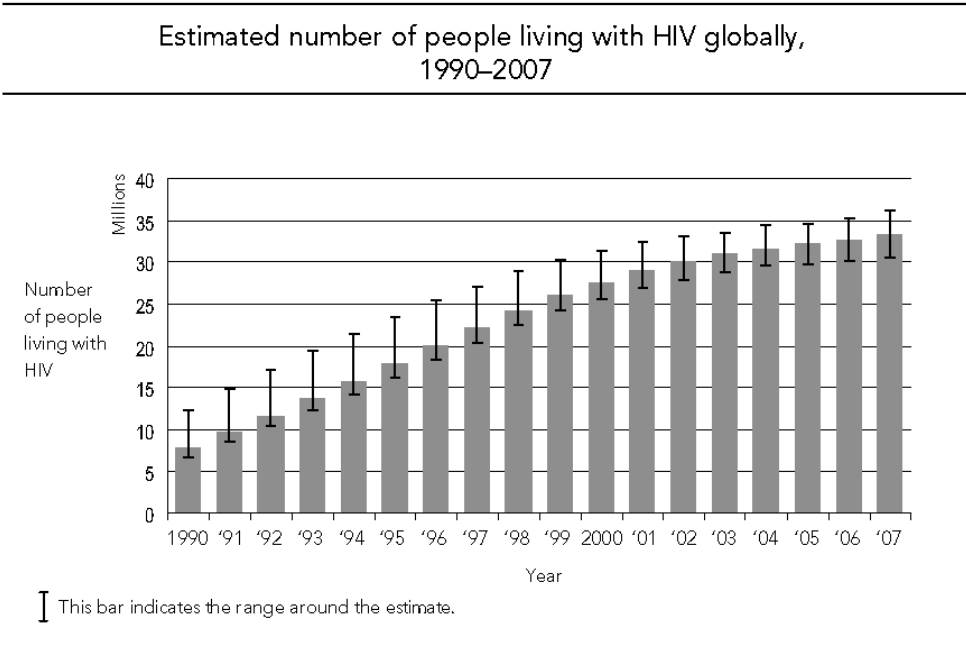


Figure 1.2: Number of people living with HIV throughout the world (1990 – 2007)
(Source: UNAIDS & WHO 2007:4)

As figure 1.2 indicates, the number of PLWHA has progressively increased between 1990 and 2007. By the end of 2007, an estimated 33 million (between 30 and 36 million) PLWHA were living with the disease throughout the world (WHO, UNAIDS & United

Nations International Children's Education Fund [UNICEF] 2009:7). It was also estimated that 29.5 million new HIV infections occurred in 2007 alone, which showed that the HIV infection rate is still on the increase throughout the world (UNAIDS & WHO 2007:3).

A recent report released in September 2009 showed that more than four million people throughout the world were receiving ART by the end of 2008; this represented a 36% increase in the number of ART users over the previous year in that year alone, and a ten-fold increase in the number of ART users over a period of five years (WHO, UNAIDS & UNICEF 2009:54). In spite of such progress, the report also indicates that an estimated five million people who were living with HIV still did not have ready access to life-prolonging treatment and care (WHO, UNAIDS & UNICEF 2009:113).

1.1.3 The human immunodeficiency virus disease in sub-Saharan Africa

Sub-Saharan Africa is the region that is most seriously affected by HIV infections, with AIDS as the leading cause of death in this region (UNAIDS & WHO 2007:15). It was estimated that, in 2007 alone, 2.1 million people (namely, 1.7 million adults and 330 000 children under the age of 15 years) died from AIDS-related causes (UNAIDS & WHO 2007:1).

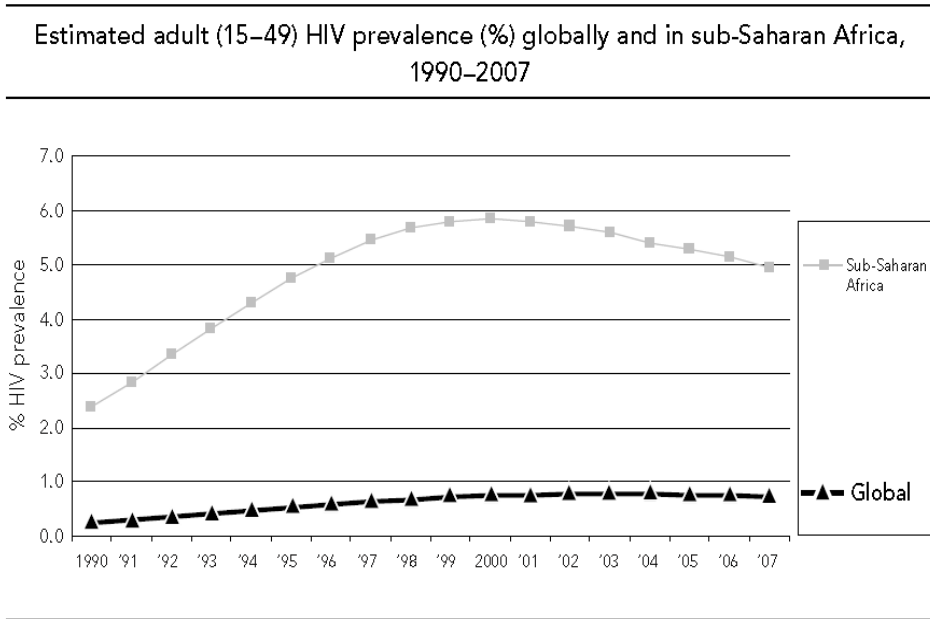


Figure 1.3: A comparison of the HIV prevalence trends globally and in sub-Saharan Africa (1990-2007)
 (Source: UNAIDS & WHO 2007:17)

Figure 1.3 shows that the global prevalence of HIV stabilised in 2000 and then embarked on a downward (reducing) trend in 2006. By contrast, there was a steep increase in the prevalence of HIV-infected people in sub-Saharan Africa from 1990. After this upward trend reached a peak in sub-Saharan Africa in 2000, it began to show a gradual decline between 2000 and 2007 (Ellman & Simms 2008:1071).

For the purposes of this research, it is sufficient to note that the number of people who are infected with HIV in sub-Saharan Africa steadily but slowly began to decline after the year 2000.

1.1.4 The human immunodeficiency virus epidemic in Uganda

Uganda is one of the sub-Saharan Africa countries that has been most severely affected by the HIV/AIDS epidemic because “more than three quarters of all AIDS deaths [throughout the world] in 2007 occurred in sub-Saharan Africa” (UNAIDS & WHO 2008:7). In recent years, a number of interventions have been implemented in Uganda to contain the HIV epidemic, and these efforts have been rewarded with some degree of success (The United States President's Emergency Plan for AIDS Relief [PEPFAR] 2008:[1]). Uganda was the first sub-Saharan country to register a drop in the number of HIV-infected patients (Asamoah-Odei et al. 2004:38; UNAIDS & WHO 2008:11). While the HIV-infection rate peaked in 1992 in Uganda, it thereafter displayed a downward trend that stabilised in 2000 and that persisted through to 2005 (Kirungi, Musinguzi, Madraa, Mulumba, Callejja, Ghys & Bessinger 2006:i38). Similar reductions in the prevalence of HIV-infections have since been reported in Zimbabwe, Rwanda, Malawi and Ethiopia (Shelton, Halperin & Wilson 2006:1121).

In addition to this, there was a levelling of the HIV-infection rate among both men and women in rural Uganda since 2000 (UNAIDS & WHO 2008:12). Since Ugandan women demonstrate a high average fertility rate of 6.7 pregnancies per woman during the reproductive phase of their lives, Uganda's population rate is growing very rapidly. Therefore, though the rate of HIV infections remained stable among the population at large, amidst a high population growth rate, this implies that an increasing number of people are becoming infected with HIV each year (UNAIDS & WHO 2008:13).

Since there are approximately 1.1 million PLWHA in Uganda, the HIV epidemic in that country remains a cause for serious concern with infections highest among urban residents (10% compared to 5.7% among rural residents) and females (7.5% compared to 5.0% among males) (Ministry of Health – Government of Uganda 2009:42; UNAIDS & WHO 2008:11).

The prevalence of HIV infections in 2004 in Uganda among inpatients in medical and surgical wards was 35% and 12% respectively, while the overall HIV burden was 38% among all inpatients (Wanyenze, Nawavvu, Namale, Mayanja, Bunnel, Abang, Amanyire, Sewankambo & Kanya 2008:302).

The cause of 70% of all deaths in the age group of patients between 25 and 44 years old has been attributed to HIV (Lopman et al. 2006:189; Nunn et al. 1997:[1]). It has been estimated that, by 2010, the crude death rate in Uganda will increase by 5.6 per 1 000 of the population because of the effects of HIV/AIDS (Stanecki & Walker 2002: 293). This implies that the crude mortality rate in the whole population will increase from 9.5 per 1 000 without AIDS to 15.1 per 1 000 with AIDS in the population at large (Stanecki & Walker 2002: 293).

In 2005, the HIV infection rate among adults between the ages of 15 and 49 in Uganda fell by a margin of 6.7% from the national average of 18% that was established in the 1990s (Ministry of Health – Government of Uganda 2006: 97,101; Uganda AIDS Commission – Government of Uganda 2008:3).

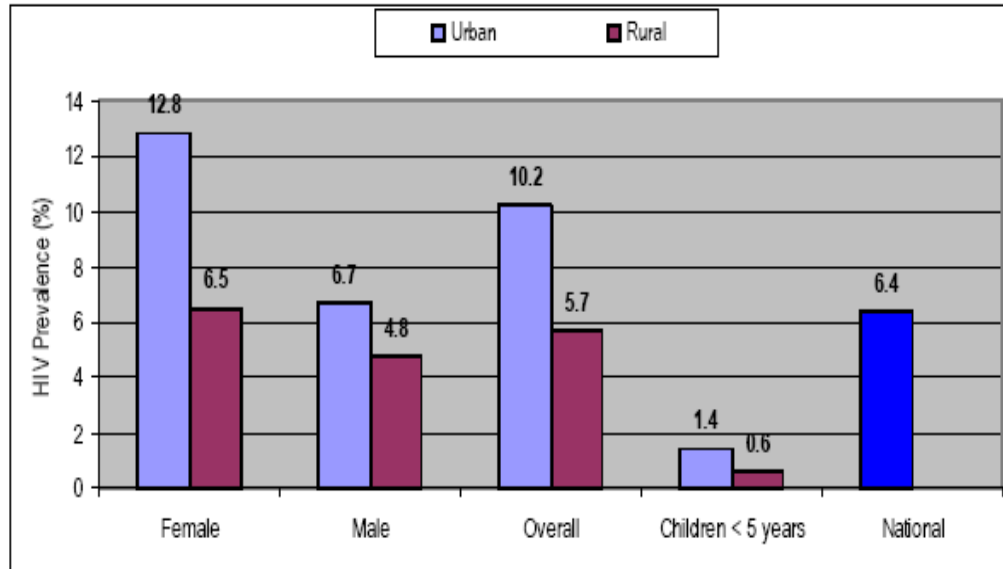


Figure 1.4: The prevalence of HIV infections in urban and rural areas disaggregated in by gender

(Source: Uganda AIDS Commission – Government of Uganda 2006a:6)

Figure 1.4 shows that the prevalence of HIV infections in the urban areas of Uganda was 10.2% in comparison to 5.7% in the rural areas. It is noticeable that the number of HIV infections is also greater among females (12.8% and 6.5% in urban and rural areas respectively) when compared to the number of infections among males (6.7% and 4.8% in urban and rural areas respectively) (Uganda AIDS Commission – Government of Uganda 2006a:6; Ministry of Health – Government of Uganda 2006:97,103).

The World Health Organisation (WHO) country profile for Uganda on HIV/AIDS treatment scale-up indicated that the sectors of the population who were most vulnerable to HIV infection in Uganda included young women, people who practised prostitution and military personnel (PEPFAR 2008:[1]). According to the UNAIDS Report on the Global AIDS Epidemic, HIV/AIDS was responsible for 91 000 deaths by the end 2005 and for 61 306 deaths by December 2008 (Ministry of Health – Government of Uganda 2009:42; PEPFAR 2008:[1]).

Since HIV/AIDS is therefore by far the most significant cause of death among Ugandans, it is a condition that requires careful monitoring and investigation. It was for this reason that Bennett, Boerma and Brugha (2006:72) recommended that evaluations

and assessments about the effect of HIV/AIDS interventions on AIDS morbidity and mortality rates should include a thorough understanding of the factors that drive these changes.

1.1.5 The impact of the human immunodeficiency virus on other diseases

While HIV has exerted a significant impact on the prevalence and incidence rates of other infections and non-infectious diseases, the contrary is also true. Thus, for example, the high prevalence of untreated sexually transmitted infections (STIs) has contributed significantly to the spread of HIV. It is also known that patients who are HIV-positive are characterised by an increased susceptibility to tuberculosis and clinical malaria (in terms of the frequency and severity of the episodes) (Corbett, Steketee, ter Kuile, Latif, Kamali & Hayes 2002:2177.)

The interaction between HIV and other infectious diseases (and vice versa) in sub-Saharan Africa is an increasingly important public health issue throughout the world. The net effect of this interaction between HIV and other infectious diseases is increased rates of transmission, morbidity and mortality. “HIV-1 has become a major endemic infection in Africa, with an unusually high potential to interact with other disorders, both through the generation of many immunosuppressed individuals and because its own infectivity and clinical course is altered by other infections” (Corbett et al. 2002:2177).

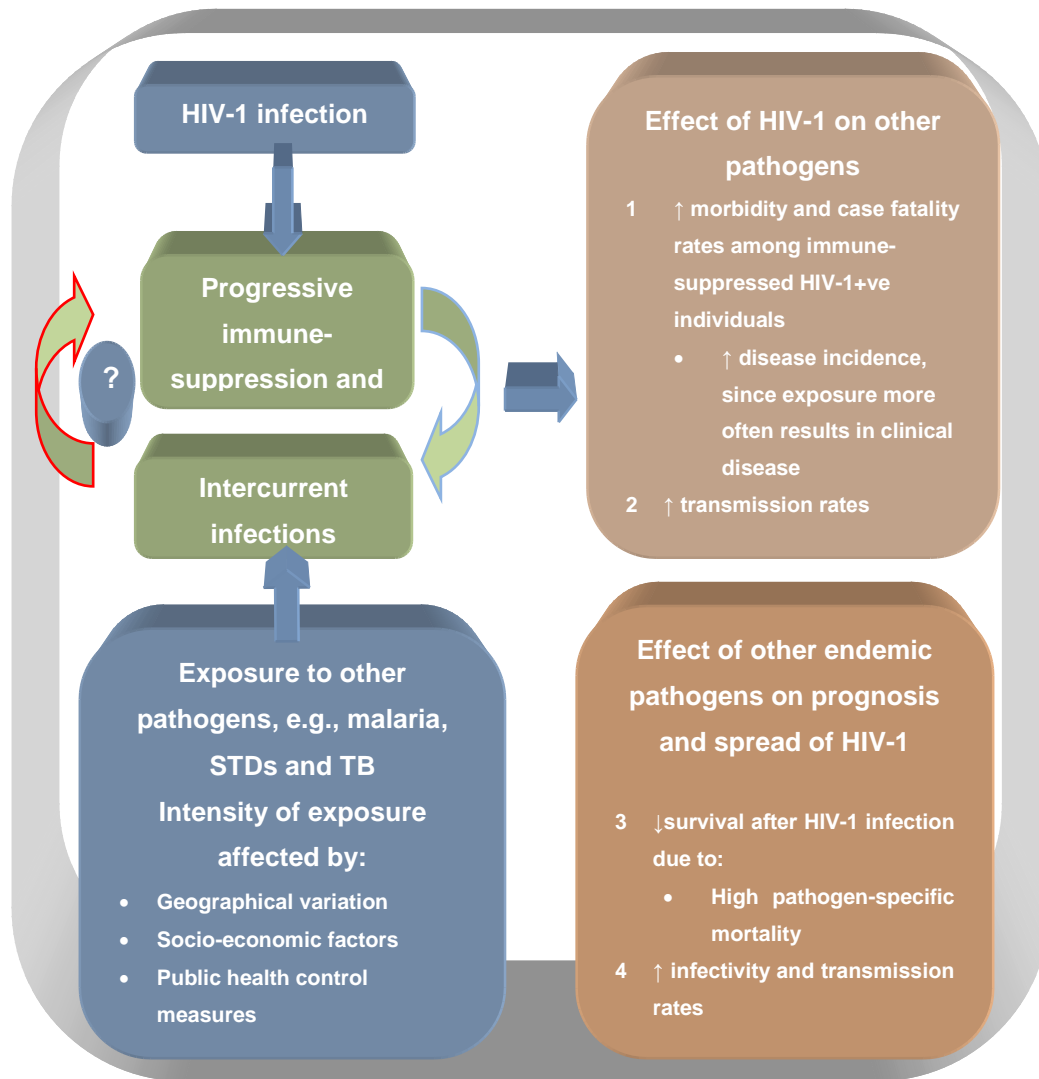


Figure 1.5: Potential interactions between HIV-1 and other infectious diseases

(Source: Corbett et al. 2002:2177)

The interactions set out in figure 1.5 (above) between HIV and other infectious diseases affect the effective control of HIV in a number of ways. The effects of these interactions between HIV and associated infectious diseases vary from one disease to another. The most notable interaction occurs between HIV and tuberculosis. This particular interaction is directly associated with an increased burden of disease that results in increased rates of mortality and morbidity (see effect one [1] and two [2] in figure 1.5 above).

But there are also other conditions and diseases that are associated with increases in transmission and morbidity. Diseases that are associated with the presence of HIV in the human body are numerous and various. HIV-infected patients have become, for example, the locus for a recent resurgence in once-rare diseases such as

cryptococcosis, enteric pathogens, bacterial pneumonia and malaria, all of which have now become common causes of morbidity and mortality in HIV-infected patients.

It has been observed, for example, that patients who are infected with HIV are far more vulnerable to various kinds of morbidity, and that their mortality rate is higher than comparable mortality rates among HIV-negative individuals infected with the same pathogens (see effect three [3] and four [4] in figure 1.5 above). Increased rates of transmission of these infectious diseases and increased HIV replication (see effect three [3] and four [4] in figure 1.5) result in an acceleration of the effect of HIV that ultimately culminates in full-blown AIDS. It is also known that HIV infectivity (see effect four [4] in figure 1.5) can be increased by the involvement of other infections, especially the kind of sexually transmitted infections that are often responsible for high HIV transmission rates in the first place.

The direct or indirect compounded effect of this increased incidence and prevalence of infectious diseases on HIV-infected and non-infected individuals poses a serious threat to the already-overextended public health systems in the countries of Africa, and it will undoubtedly exert a significant effect on future survival trends (Corbett et al. 2002:2177).

1.2 BACKGROUND TO THE RESEARCH PROBLEM

The greatest impact of HIV/AIDS over the past two decades on rural communities in Uganda is that it has increased mortality rates. HIV/AIDS-related mortality and morbidity have significantly contributed to the overall burden of disease and death with which Ugandan health services have had to cope. It has been estimated that of the 2.6 million people who were infected by HIV, approximately 1.6 million have already died of HIV-related illnesses and conditions. Most of these people were in the most productive age groups that range between 15 and 49 years old. The loss of so many people from the country's most economically and educationally active population sector has obviously affected the productivity of Uganda, and bodes ill for a future in which the accumulated talents and ability of such people would have been decisive for the progress and welfare of their country (Uganda AIDS Commission – Government of Uganda 2008:12). It has also been estimated that 130 000 new HIV infections continued to occur annually in Uganda (Uganda AIDS Commission – Government of Uganda 2008:12). HIV is

therefore currently responsible for the enormous burden of disease in Uganda. A proportionately huge number of people have already died from the HIV virus, and, of those who are still alive, a large number continue to succumb to the effects of HIV/AIDS every year.

Mermin, Were, Ekwaru, Moore, Downing, Behumbiize, Lule, Coutinho, Tappero and Burnell (2008:752) state unequivocally that “antiretroviral therapy [ART] is the most effective clinical intervention for reduction of mortality in people with HIV-1 infection”. The key objective in encouraging HIV-infected people to participate in freely available ART treatment programmes in high-prevalence, low-resource settings is therefore, firstly, to reduce as far as possible the extremely high levels of morbidity and mortality that are associated with the prevalence of HIV/AIDS among patients. Secondly, to reduce the devastating and destructive effects that such levels of morbidity and mortality have on urban and rural communities and on the limited resources of the health care system. By 2003, 100 000 people living with HIV/AIDS in sub-Saharan Africa were participating in free ART programmes. This figure rose to 810 000 by the end of 2005 – only two years later (WHO 2006a:7). By the end 2008, three million people who were living with HIV/AIDS in sub-Saharan Africa were actively participating in ARV treatment programmes (WHO, UNAIDS & UNICEF 2009:54).

While the monitoring of HIV trends is still dependent upon sentinel surveillance at selected antenatal clinics, there is little or no monitoring of the overall impact that ART programmes make on the mortality rates that prevail in all facilities that provide free access to ART (Asamoah-Odei et al. 2004:40). By 2008, freely available ART in the health care facilities of Uganda had been available for more than four years (i.e. since 2003) (Uganda AIDS Commission – Government of Uganda 2008:25). In Uganda, there are 286 ART sites including hospitals and health centres (Uganda AIDS Commission – Government of Uganda 2008:26).

This annual increase in the access that HIV-infected people have to free ART in the rural communities of Uganda is therefore expected to diminish and ultimately reverse the mortality rates that are attributed to the effects of HIV/AIDS. “Knowledge is lacking with respect to which combination of prevention and treatment strategies work best, and under what circumstances” (Bennett et al. 2006:79). There is therefore an urgent need to identify, analyse and assess the numerous ways in which HIV/AIDS increases the

mortality rate in countries such as Uganda, and to determine the impact of ART on mortality rates because some aspects of the HIV/AIDS mortality equation are not yet fully understood and because, as Bennett et al (2006:79) point out: “The global commitment to scale up HIV/AIDS services is a huge experiment.” These researchers have also pointed out that “there is need for data to demonstrate the effect and [to] secure future funding” (Bennett et al. 2006:79).

The introduction to this chapter and the explanation of the background to the HIV/AIDS epidemic in Uganda that the researcher presented in this section indicate that it is likely important for both those responsible for the programmes and the public at large need to appreciate the beneficial effects of free access to ART for those who are HIV-positive or suffering from the effect of AIDS. It is therefore vitally important to understand the factors that influence the mortality and morbidity trends in the rural settings of Uganda. After four years of access to free ART in the rural areas of Uganda, a study of this kind should be able to provide some useful answers to the questions raised by the genuine concerns of the people of Uganda about the devastating effects of the HIV epidemic. The researcher feels that that carefully planned research and the correct implementation of properly designed interventions should be able to achieve the *ultimate goal* of making ART freely available to HIV-infected people: that goal is, of course, *a significant and meaningful reduction in current morbidity and mortality rates*.

The purpose of this study was therefore to investigate the mortality trends before and after the introduction of free antiretroviral treatments in a selected rural setting in Mpigi district of Uganda in order to obtain a more comprehensive view of the successes and challenges that result from the implementation of the ART programme in Uganda. The results of this study have provided a useful practical and theoretical basis for the ongoing monitoring of mortality trends and the implementation of targeted interventions. The study has also emphasised the critical importance of the role that health managers should play in the refinement, maintenance and extension of the scope of hospital records systems. It is only when hospital records are meticulously designed and maintained by the nursing, medical and administrative personnel of a hospital that they are capable of indicating which patients are most at risk of future HIV infection. When such predictions can be made on the basis of reliable and comprehensive hospital and clinic record-keeping, it will be possible for health care personnel to arrange and manage access for HIV-infected patients to ART. This factor alone will exert a profound

and significant impact on the mortality rates that result from HIV infection and the progression of AIDS in affected patients.

The results and recommendations of this study will benefit the health status of the citizens of Uganda and other countries because it provides a rational explanation of those factors that contribute and cause the high mortality rates that are associated with HIV/AIDS. Many of these factors have not yet been adequately investigated and described. This research also indicates how important it is for health systems to monitor mortality trends because they are a key indicator to the quality and efficacy of health service delivery in any country. Although this research focuses on the situation in Uganda, the findings of this study should be equally applicable to all countries in which HIV is the most common current precursor to morbidity and death.

1.2.1 Country profile: Uganda

This short introductory section will orientate the reader with regard to the position of Uganda in Africa and the world. It therefore offers a brief profile of the Uganda and the countries that surround it.



Figure 1.6: Map of Africa indicating the location of Uganda

(Source: Department of Peacekeeping Operations – Cartographic Section – United Nations 2004:[1])

While figure 1.6 sets Uganda in the context of the other countries of Africa, figure 1.7 contains a much closer review of the countries that border Uganda, and indicates the situation of the Mpigi district where this study was conducted. The Republic of Uganda is a land-locked African country that is situated in East Africa. Uganda shares common borders with Kenya in the east, Tanzania in the south, Rwanda in the south-west, the Democratic Republic of Congo in the west, and Sudan in the north (see figure 1.7: Map of Uganda).

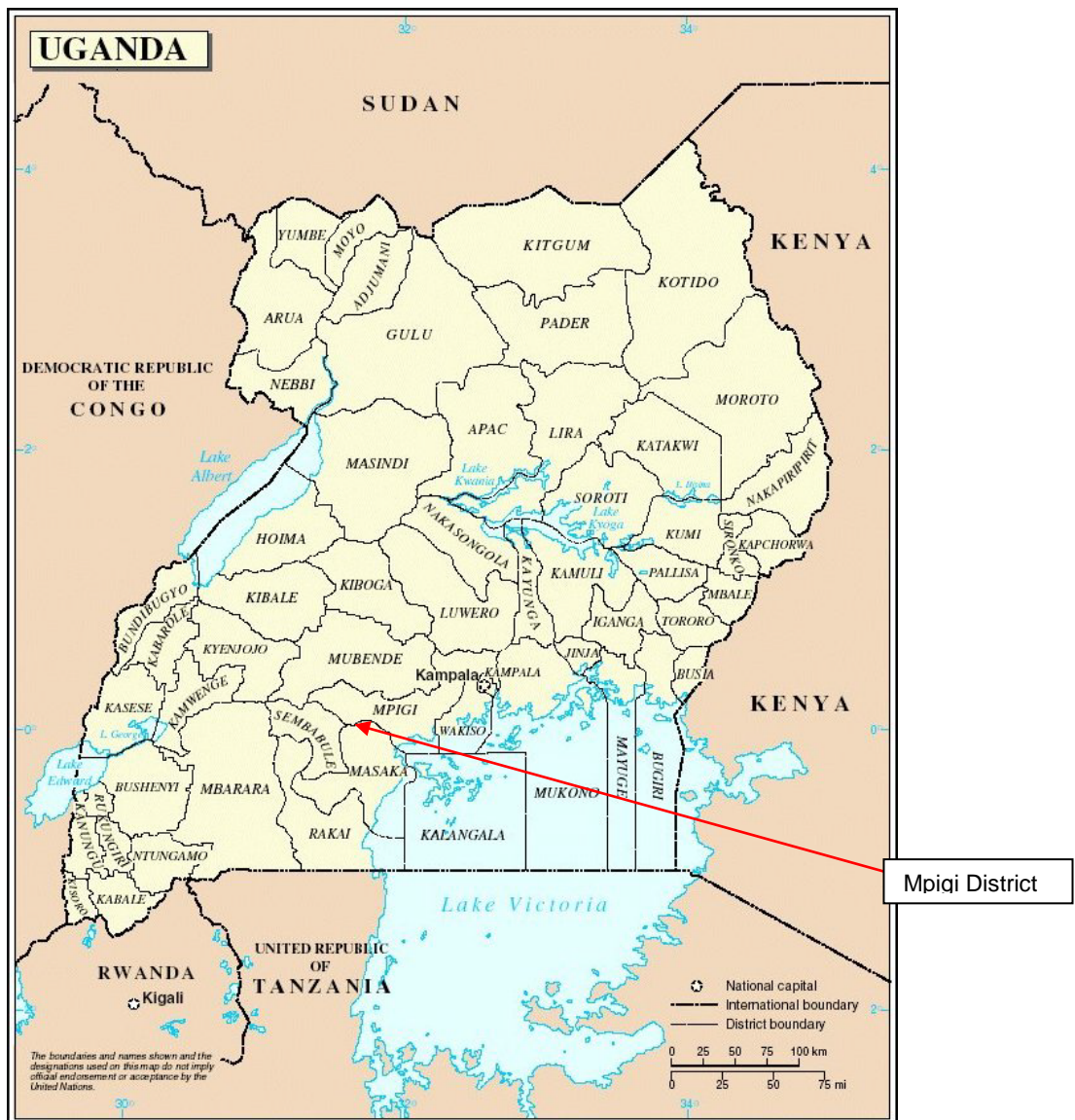


Figure 1.7: Map of Uganda indicating the location of Mpigi district

(Source: Department of Peacekeeping Operations – Cartographic Section – United Nations 2004:[2])

Figure 1.7 shows where the Mpigi district is located in Uganda. This district is surrounded by the Masaka and Kalangala districts in the south, the Wakiso district in the east, the Sembabule district in the west, and the Mubende and Luweero districts in the north.

Although Uganda is land-locked, it covers a total area of 241 038 square kilometres with Lakes Victoria in the southern border, Albert and Lake Edward on the western border. From an administrative point of view, it is divided into 79 districts, and it operates on the basis of a decentralised local governance system (Uganda AIDS Commission –

Government of Uganda 2008:1; Uganda Bureau of Statistics – Government of Uganda 2006a:1). The total population of Uganda in July 2008 was estimated to be 31 367 972 (Central Intelligence Agency 2008:[1]). It was also estimated that about 86.9 of the population lived in rural areas and that 61.2 % of the whole population could be classified in the age groups of between 10 and 59 years old (Uganda AIDS Commission – Government of Uganda 2008:1). At the annual population growth rate of 3.2% per annum (United Nations Development Program [UNDP] 2007:21; Uganda Bureau of Statistics – Government of Uganda 2006c:viii), Uganda is reported to have one of the highest population growth rates globally. This population growth rate can be compared to the average of all the other sub-Saharan Africa countries, which have a population growth of 2.4% (Uganda AIDS Commission – Government of Uganda 2008:1).

The age distribution of Ugandans is as follows: 50% of the population are between zero and 14 years of age; 47.8% of Ugandans are between 15 and 64 years old, and 2.2% are 65 years old or older (CIA 2008:[1]). One may therefore regard Uganda as a predominantly “young” society because nearly half of its population is within the sexually active and reproductive phases of human development.

The mortality rate of adults in Uganda is 9.3 and 8.2 per 1000 of the population for males and females respectively (Uganda Bureau of Statistics – Government of Uganda 2006a:278). The life expectancy at birth is 52.3 years (CIA 2008: [1]). AIDS has exerted a considerable effect on the average Ugandan’s life expectancy, on the infant mortality, and on exceptionally high mortality rates. It has also created a number of anomalous and unusual effects in population distribution when these factors are examined in terms of age and gender (CIA 2008:[1]). The burden of disease throughout the country is abnormally high if one compares it to that which the country experienced in the years before 1980. This is a direct result of the excessive mortality that results from HIV- and AIDS-related illnesses.

1.2.2 Profile of the Mpigi district

Mpigi is a rural district situated in central Uganda (see figure 1.7). Mpigi town is the main town of the district, and is located approximately 35 km south of the capital city of Uganda, Kampala. The district occupies a total area of 3 714.9 km² (Mpigi District Information 2008:[1]).

The 2002 national census revealed that the Mpigi population was 414 757 in that year (Ministry of Health – Government of Uganda 2003a:14).. The population growth rate in the Mpigi district is 1.3% (Uganda Bureau of Statistics, Government of Uganda 2006a:47), therefore, the projected population of Mpigi district in June 2008 was 446 930. Only 7% of the people who live in the Mpigi district actually live in urban areas, and the rural communities are often remote and widely dispersed (Uganda Bureau of Statistics – Government of Uganda 2006c:46).

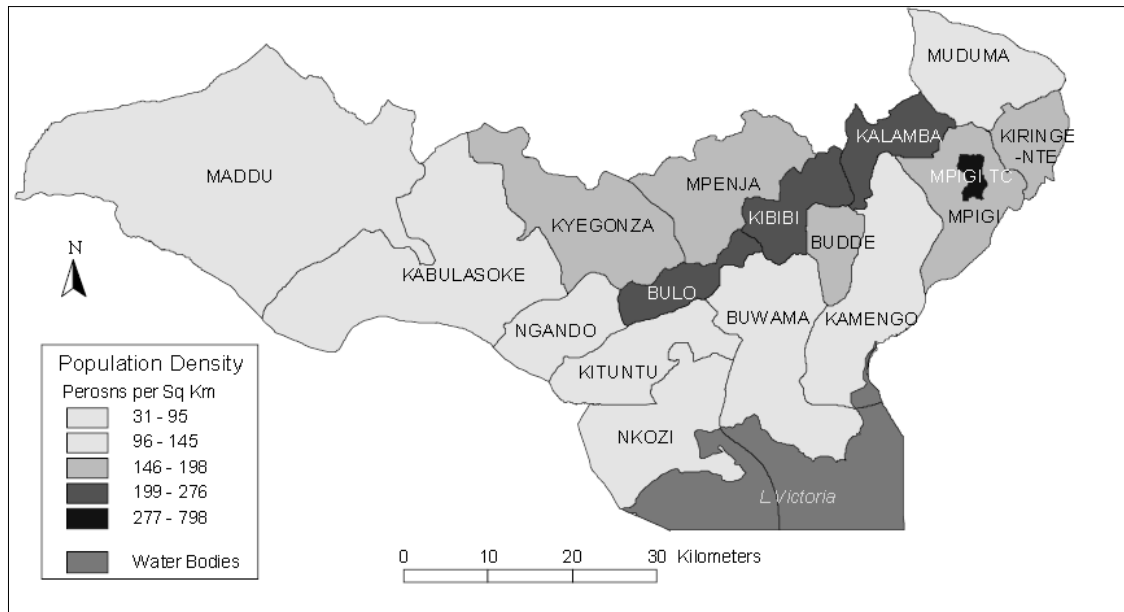


Figure 1.8: A map of the Mpigi district that indicates the sub-counties
(Source: Mpigi District Local Government 2008:11)

The Mpigi district consists of 17 sub-counties (see figure 1.8 above) and four counties. The hospital in which the researcher conducted his investigations for this study is situated in the Nkozi sub-county of the Mawokota South county, which consists of the Nkozi, Kituntu and Buwama sub-counties. The main language spoken by the people who live in the Mpigi district is Luganda. The major economic activity in the district is agriculture, and food crops such as sweet potatoes, beans, cassava, maize, bananas, groundnuts and coffee are all actively cultivated by the local population (Mpigi District Information 2008:[1]).

1.2.3 Health services in the Mpigi district

The health services in the Mpigi district are organised in terms of the National Health Policy set out by the Ugandan government which has decentralised health services to

the level of health sub-districts. A *health sub-district* in this context is defined as the operational unit at county level that is mandated with the responsibility of delivering the minimum health care package that the government makes available to the people of Uganda (Ministry of Health – Government of Uganda 2005:20).

The health system is divided and organised into levels II, III and IV. The Mpigi district has 27 health units at level II, which is the first level of care in the community and which offers out-patient services. Level III offers basic preventive, promotive and curative services and also supports level II facilities. Mpigi has 23 level III facilities. The highest level in the district is level IV which consists of two hospitals and two health centres. The facilities that provide level IV care are also referred to as *health sub-district headquarters* and they are responsible for providing leadership, preventive, curative and surgical services, and together they constitute the physical base of the health sub-district management team (Ministry of Health – Government of Uganda 2005:20.)

While a level II health centre serves a catchment population of approximately 5 000, level III facilities offer services to an average population of up to 20 000. Level IV facilities are staffed by resident medical officers and cover a population of up to 100 000. A general hospital covers a population of between 100 000 and 1 000 000 people (Ministry of Health Uganda 2000:11, 12, 71.)

This study focused on only one of the four health sub-district headquarters in Mpigi, which is responsible for one of the two hospitals in the district.

1.3 PROBLEM STATEMENT

In the 1990s, the rural communities of Uganda and other developing countries (but especially those in sub-Saharan Africa) experienced very high levels of HIV infections (WHO & UNAIDS 2004a:25). This high HIV infection rate was directly associated with the significant increase in mortality rates that were generated by the opportunistic infections that are characteristic of the advanced stages of HIV/AIDS. In Mwanza in the United Republic of Tanzania and in Rakai in Uganda, HIV was a causative factor in between 50% and 66% respectively of all the deaths during this period (Lopman et al. 2006:189).

It was in the early 2000s that access to free ART for all members of the HIV-infected population was first “rolled out” (initiated) in Uganda. This programme was subsequently extended in scope and intensity in Uganda and in 14 other developing countries, and was supported financially and in other ways by the PEPFAR, the Global Fund, and the WHO (Mermin et al. 2008:758). While the “roll out” of free access to ART in Uganda began in 2003, it has since been expanded to offer ART to 106 000 PLWHA in 2007 and to 153 718 PLWHA by December 2008 (Ministry of Health – Government of Uganda 2009:42; Mermin et al. 2008:758).

Ever since the roll out of free access to ART, observers in Uganda have noted the impact of the efforts that have been made since 2002 to minimise the impact of HIV/AIDS on the population of Uganda. The success of the programme to make ART freely available to those who needed it is evident from the following reported observations:

- Uganda was able to report a reduction in the prevalence of HIV infection from 13.0% (in the early 1990s) to 4.1% (by the end of 2003) (WHO & UNAIDS 2004a:25).
- Free antiretrovirals (ARVs) have also been freely available to the public through public and private-not-for-profit [PNFP] hospitals for more than four years (Uganda AIDS Commission – Government of Uganda 2008:25).
- Health care workers such as medical doctors, clinical officers, pharmacists, nurses and other categories of health care providers (such as laboratory staff who offer health-related services) have been trained in large numbers in the counselling, diagnosis and management of HIV and HIV-related illnesses (Uganda AIDS Commission – Government of Uganda 2008:24).
- Mermin et al (2008:757) reported a 90% reduction in the mortality rate among HIV patients who adhered strictly to their ART regimen in Uganda.

1.3.1 The impact of antiretroviral therapy on morbidity and mortality rates

A large number of researchers and experts have asserted that ART has contributed to the decline in HIV-related illness and death in HIV-positive individuals in developed countries (Beck, Mandalia, Williams, Power, Newson, Molesworth, Barlow, Easterbrook, Fisher, Innes, Kinghorn, Mandel, Pozniak, Tang & Tomlinson 1999:2160; Mocroft,

Ledergerber, Katlama, Kirk, Reiss, d'Arminio Monforte, Knysz, Dietrich, Phillips & Lundgren of The European Union Research Strategy to Infections Diseases [EuroSIDA] Study Group 2003:22-29; WHO & UNAIDS 2002:3). In addition, Carter (2005:[1]) is of the opinion that “consistent with the introduction of potent anti-HIV treatment, admissions fell from 129,000 in 1996 by 25% to 97,000 in 1998 and by a further 6% to 92,000 in 2000”.

The four years from June 2004 to June 2008 when free ART access was available in Uganda have resulted in major health gains that have unfortunately been inadequately documented. An insufficient amount of research has been undertaken to address key issues about the effect and long-term impact of ART on morbidity and mortality trends in poorly resourced countries. The National HIV/AIDS programmes in sub-Saharan Africa confined themselves only to monitoring the number of patients who are using ART in a systematic way and the prevalence and incidence of HIV as indicators of the success or otherwise of their HIV interventions. But they have neglected to keep careful track of the mortality trends and patterns that are the focus of this study, and which need to be monitored if researchers and administrators wish to know just how effective (or otherwise) these ART programmes have been.

Knowledge about the extent of ART access on the part of those who need it remains a crucial limitation to the successful implementation of ART programmes. We know, for example, that in 2008, ART in sub-Saharan Africa was being accessed by 44% (41%-48%) of those who needed it. This means that more than five million people who needed ART were not accessing treatment. It is information such as those that makes “it absolutely critical to accelerate programme delivery to reach universal access goals” (WHO, UNAIDS & UNICEF 2009:5). Such limitations in ART coverage contribute to late start of treatment (or a further discussion of this point, see 1.3.2 below) and to the discontinuation of treatment at one stage or another during the course of treatment. It has also been determined that inadequate coverage contributes to a higher degree of erratic or “intermittent” use of ARVs on the part of who have commenced treatment. The intermittent use of ARV medications results in poor adherence rates to ARV dosage requirements, and this ultimately negates the potential beneficial effects of ART for the patients themselves and can make the drugs become increasingly resistant to HIV in the long term. But the concept of the free universal access to ART for those in need of it is, therefore, of the utmost importance for ensuring that the ultimate objective of

reducing morbidity and mortality in the general population is achieved. Limitations of access that include interruptions in the supply of ARVs is one of the main reasons why the high HIV/AIDS mortality rates in developing countries continues to persist (Wood Montanera, Bangsberg Tyndalla, Strathdeed, O'Shaughnessya & Hogga 2003:2424).

Late access to treatment also affects mortality trends among patients who are being treated by ART. Before 2003, the high cost of ART was the main reason why many patients who needed ART medications were unable to access them. But since ART has become freely available in most sub-Saharan African countries that have functioning health care systems, other factors such as socio-economic status, race, gender, the perceived stigma of being HIV-positive, geographical factors, cultural barriers and the hesitation of some physicians who should be actively encouraging their patients to participate in ART, are increasingly playing a significant role in limiting access to these free medications (Wood et al. 2003:2421, 2422).

The commencement of ART *before* the manifestation of advanced forms of HIV disease that tend to occur concurrently with very low CD4 T cell counts, are reported to be associated with more favourable long-term prognoses and better patient survival rates (Rosen, Fox & Gill 2007:1698; Wood et al. 2003:2421. The contrary is also true because very low CD4 count levels (and especially counts of less than 200 cells/ μ l) usually indicate a poor prognosis. In an a review of mortality trends among patients on ART in sub-Saharan Africa, the median baseline CD4 T cell count ranged from between 43 and 147 cells/ μ l. This was also associated with a short median duration of follow-up ranging from between 3 and 46 (Lawn, Harries, Anglaret, Myer & Wood 2008:1898.) It is important to note that late initiations of treatment have been widely reported in sub-Saharan Africa even though such late commencements continue to be a critical factor in the success or otherwise of ART services – especially in settings with inadequately financed, staffed and managed facilities.

Poor or intermittent adherence to ARV dosage regimens and low patient retention rates also exert a highly negative effect on the mortality trends in ART programmes. Rosen et al (2007:1696) reported an average attrition rate of 22% in sub-Saharan Africa. The death of the patients concerned and the failure to pursue follow-up (for whatever reason) were responsible for 40% and 56% respectively of the incidence of attrition. WHO has reported an attrition rate of 25% at 12 months and 33% at 24 months (WHO,

UNAIDS & UNICEF 2009:5). While attrition rates continue to be so high in high prevalence settings, it is unlikely that ART programmes will significantly improve the morbidity and mortality trends in hospital settings.

1.3.2 Limitations on the optimisation of antiretroviral treatment

There are four major factors reported by researchers that may limit the optimisation of the benefits of ART.

Firstly, Carter (2008:[2]) reports a significantly higher risk of deaths in South Africa among HIV/AIDS patients because patients are given ART when the AIDS-related diseases and conditions that are associated with HIV have reached an advanced stage of manifestation. It therefore seems probable that late diagnoses in combination with the commencement of ART treatment when the health status of patients has already been significantly undermined (especially in low resource settings such as Uganda) will be unlikely to result in significant long-term reduction in morbidity and mortality.

Secondly, Uganda is deficient in the infrastructural and program monitoring systems that enable physicians adequately to monitor the viral loads and CD4 counts of all patients whenever they report for diagnosis and follow-up. This places physicians in a very difficult position because they are unable to track the success or otherwise of the ART that has been offered to the patient. This absence of monitoring systems contributes to the inability of the health care system to reduce mortality rates among HIV-positive patients (Jahn, Floyd, Crampin, Mwaungulu, Mvula, Muntali, McGrath, Mwafilaso, Mwinuka, Mangongo, Fine, Zaba & Glynn 2008:1607).

Thirdly, Mermin et al (2008:758) reports how the effects of rampant poverty have prevented HIV/AIDS patients from successfully accessing and utilising ART. Poverty also prevents patients (and especially patients from rural areas) from producing the necessary transport fees that will enable them to keep follow-up appointments at their health care facilities. Poverty thus contributes to poor attendance rates at clinics and prevents patients from renewing their prescriptions by obtaining refills of their medications. This also interrupts the regularity with which these medications should be taken (a factor that is especially important with ARV) medications and it prevents patients from being examined for the secondary infections or any other AIDS-associated

symptoms. Poverty also obviously contributes to poor nutrition and this in itself results in a progressive deterioration in the health condition of HIV/AIDS patients on ART. All these factors that result from the poverty of the patients concerned are endemic among ART patients in developing countries.

Fourthly, the poverty of many patients in developing countries and the limited resources they have to pursue follow-up and surveillance, negatively affect ART patient retention rates and thus limit the benefits that properly administered ART can have on prospects for patient survival (Mermin et al. 2008:758; Rosen et al. 2007:1696). Since poverty contributes to below-optimal adherence levels, it also increases the probability of poor treatment outcomes and the development of resistance in ARV medications (WHO 2005a:[1]).

Increased access to ART is beset by a number of barriers and challenges that are discussed in detail in section 2.10. But as more and more people make use of ART but fail to use it as rigorously as it should be used, HIV drug resistance increases and this creates a whole range of problems for future and current ART users (Bartlett & Shao 2009:644). Other notable challenges faced by ART programmes in resource-limited settings include insufficient funding, inadequate diagnostic facilities, a lack of properly qualified staff and serious defects in (or the simple absence of) adequate data management systems (Miti 2008:[1]).

Although the significance of these factors varies from place to place and depends on the magnitude of these problems experienced, the impact that they make on mortality rates should not be underestimated. Such challenges may negate most or all of the advantages that patients may gain by having free access to ART in the first place. Another negative outcome may be that mortality rates merely remain more or less static or (worse) may even increase over time – even for patients who are being treated with ART. When it becomes evident that the mortality rate of patients on ART is not decreasing, one may expect that mortality rates in general will either stagnate or increase.

1.3.3 Goal and purpose of antiretroviral treatment

The reduction of morbidity caused by HIV- and AIDS-related illnesses and conditions, and the subsequent reduction in the general mortality rate of the affected population, remains the ultimate goal of any ART programme. This is especially true for programmes that have been designed for populations in which the rate of HIV infections is far above the national population average. The current goal of antiretroviral treatments is to reduce the HIV viral load in each individual patient to the lowest possible level until the virus becomes undetectable by means of normal tests, and then to maintain patients in that state of equilibrium for as long as possible (Amoroso, Davis & Redfield 2002:323). In order to achieve this, it is essential to enroll as many HIV-infected people in need of ART as possible in an ART programme.

But this kind of programme can only be effective if the mortality and morbidity rates of patients who are enrolled in the programme are continuously monitored so that the health care personnel who administer the programme will be able to judge the effectiveness or otherwise of the programme that they administer. Unless this is done, there is no way of knowing (apart from unreliable anecdotal observations) just how effective an ART programme might be. Continuous monitoring is therefore an essential component of any serious ART programme. The obvious and logical assumption is that after four years of increased access to free ART in rural hospitals, in combination with other factors, one should be able to observe a notable reduction in the prevalence of HIV in a country such as Uganda where, as indicated above, the overall mortality rates are expected to exhibit a downward trend. The key objective of this particular study was, therefore, *to determine the trend of adult mortality over a six-year period.*

The accurate determination of mortality trends will provide a “reality check” or benchmark for programme managers in Uganda, and it will enable them to review mortality trends and identify deficiencies, problems and challenges in the provision of ART access. This, in turn, will enable managers to administer ART programmes in such a way that they will be able to radically to reduce rates of patient mortality. It was because there was an urgent need to obtain reliable data about mortality trends in Uganda after free access to ART had been introduced, that the researcher undertook this study in a particular rural community that, he believed, could serve as a microcosm of the wider trends in Uganda as a whole.

Even three years after free ART had first been made available in hospital settings across Uganda, there was no reliable data in terms of which adult mortality trends were occurring could be evaluated. It was therefore essential to obtain the kind of data that would enable researchers to review the effect of free ART delivery on the overall adult mortality trends – especially in rural settings where one encounters the highest rates of HIV/AIDS mortality. It was obviously essential for researchers and administrators to be able to evaluate the effect of making ART freely available to HIV-infected people so that the effects of the programme in Uganda could be measured and compared to similar programmes in other settings in the developed world.

Not only was it important to be able to track the impact of the ART roll-out on the mortality rates of HIV/AIDS patients; there was also an urgent need to be able to track the mortality trends that were being caused by other significant diseases. Corbett et al (2002:2177) have explicitly recommended that any increased access to HIV prevention and care should be accompanied by an intensified routine programme of public health surveillance so that all who are concerned with the problems of health care in Africa will be able to acquire an accurate understanding of the current realities of infectious disease control in Africa. Statistics and information from those countries where mortality and morbidity rates have been monitored over the past two decades have revealed that there has been an enormous resurgence in other serious and potentially fatal infectious diseases such as treatment-resistant tuberculosis and malaria (McMichael, McGhee, Shkolniko & Valkonen 2004:1155).

From the introduction above and the information that the researcher has provided, the following question suggested itself as the basis for detailed research:

What was the overall trend of mortality in a rural hospital setting since the introduction of free ART in Uganda?

This study therefore undertook to determine the mortality rates, mortality trends and causes of adult mortality in a particular rural hospital in Uganda. The study period was a six year period, three years before introduction of free ART (pre-free ART era) and three years after introduction of free ART (post-free ART era) from the time this research was undertaken.

1.3.4 Research questions

The high prevalence of HIV/AIDS in Uganda increased the overall morbidity and mortality rates of those who were infected by the virus. At the time when this study was undertaken, it was more than three years since free antiretroviral medications (ARVs) had been made available to the HIV-infected population of Uganda. In spite of the inadequate monitoring of mortality and morbidity trends in rural hospitals in Uganda, the following questions required urgent answers:

- What trends did adult mortality and morbidity rates reveal when one compared the period before ART became freely available to the period after ART became freely available in the rural hospital in the Mpigi district of Uganda?
- What overall effect did the availability of free ART access have on the rates of morbidity and mortality in the rural hospital in Mpigi district of Uganda?
- What recommendations could one make that will ensure that the provision of free ARVs is more effective so that they would reduce the high mortality rates that were being experienced in Mpigi district and in similar settings in Uganda?

1.4 PURPOSE AND OBJECTIVES OF THE STUDY

The overall purpose of this study was to identify and analyse the mortality trends and demographic characteristics of the patients who died in the rural hospital in the Mpigi district of Uganda over a period of six years. The researcher therefore undertook to investigate the mortality trends in terms of causes and the percentage of deaths that were known to be associated with HIV- and AIDS-related illness both before and after free ART became available to the people lived in the rural setting in the Mpigi district.

1.4.1 Study objectives

The researcher defined the specific objectives of the study in the following way:

- To investigate the trends exhibited by adult hospital mortality rates and to compare the trends of the pre-free ART period to the trends of the post-free ART periods in the rural hospital in the Mpigi district of Uganda.
- To determine the overall effect of free ART access on hospital mortality rates in the rural hospital in the Mpigi district of Uganda.
- To make recommendations about ways in which the provision of free ARVs could be administered so that the exceptionally high mortality rates in the Mpigi district and in similar settings in Uganda could be radically reduced.

1.4.2 Assumptions of the study

An *assumption* is an opinion that is believed to be true for the matter in hand although there may be no immediate evidence that proves its veracity (Polit & Beck 2006:495). The researcher made the following assumptions other purposes of this research:

- All hospital-based deaths were recorded and certified, and this contributed to the available data about the practice of hospital-based medicine and nursing science in the hospital concerned.
- All hospital-based deaths have been investigated and recorded in terms of primary and associated causes of death by qualified health care personnel.
- ART was freely and uninterruptedly available to all HIV-infected patients in the hospital in which this study was conducted ever since it was first introduced to the catchment population who used the hospital concerned as their primary source of health care.

1.5 DEFINITION OF KEY TERMS

For the purpose of this study, the researcher defined the terms that were used in this study below in the following way:

1.5.1 Acquired immunodeficiency syndrome

Acquired immunodeficiency syndrome - AIDS is an acronym that is made up of the following letters, each of which has a different meaning:

A – Acquired: AIDS is called an acquired disease because it is a disease that one must “acquire” or obtained from another infected person or medium such as an infected needle or blood. It is not therefore a condition that can be inherited or transmitted genetically.

I – Immune: This component of the acronym refers to the fact that the disease works to undermine and eventually destroy the human body's immune system. The immune system represents that physiological function of the human body that is programmed to resist and destroy invasive hostile entities such as bacteria, viruses and other disease-causing agents.

D – Deficiency: The word “deficiency” in the acronym AIDS refers to the fact that the disease undermines the human immune system so extensively that it becomes unable to function properly – and is therefore “deficient” or disabled.

S – Syndrome: The word “syndrome” is used to describe AIDS because an HIV-infected person will gradually deteriorate and become susceptible to a wide range of different diseases, morbid conditions and opportunistic infections, one or another of which will eventually prove fatal to the human host. Since the immediate cause or causes of death in each AIDS suffering varies from person to person, the ultimate effects of the HIV virus are characterised as a “syndrome” (San Francisco AIDS Foundation 2008:[3]).

HIV is transmitted by means of infected human bodily fluids for example semen and blood, through unprotected sexual intercourse (sexual intercourse without condoms), the use of HIV-contaminated hypodermic syringes, and by means of a placental transfer from an infected mother to her foetus. Although no cure or vaccine has been developed for the prevention of infection in a person who has been positively exposed to HIV, a number of antiviral drugs are available that can decrease the viral load in the body of patients and the potentially lethal infections to which patients with AIDS can become

exposed. AIDS is defined in an adult when at least two major signs and one minor sign appear in a patient in the absence of other known causes of immunosuppression such as cancer or severe malnutrition. The major signs of HIV/AIDS include a weight loss of more than or equal to (\geq) 10% of body weight, chronic diarrhoea for more than ($>$) 1 month, and prolonged fever >1 month. Minor signs of HIV/AIDS disease include a persistent cough for >1 month, generalized pruritic dermatitis, recurrent episodes of herpes zoster, oro-pharyngeal candidiasis, and generalized lymphadenopathy. The presence of either generalized Kaposi's sarcoma or cryptococcal meningitis is also regarded as sufficient evidence for a positive diagnosis of AIDS (Grant & De Cock 2001:1475; WHO 1986:72.)

AIDS can also be diagnosed in an HIV positive person who has a CD4 (T-cell) count of less than 200 cells/ μ l or one or more of the opportunistic infections mentioned above (San Francisco AIDS Foundation 2008:[4]). A diagnosis of AIDS is not revealed by means of laboratory tests but is based on the clinical presentation of a patient. AIDS is also defined as a "disease of the human immune system that is characterized cytologically especially by a reduction in the numbers of CD4-bearing helper T cells to 20 percent or less of normal – thereby rendering the subject highly vulnerable to life-threatening conditions" (Merriam Webster's Dictionary 2009a:[1]).

In this study, the term "AIDS" is used to describe a clinical condition that is caused by HIV and that is responsible for most of the widespread adult morbidity and mortality that one encounters in Uganda.

1.5.2 Antiretroviral treatment

Antiretroviral treatment or therapy or "ART" is defined as the use of a combination of at least three drugs that will typically include either a protease inhibitor or non-nucleoside reverse transcriptase inhibitors (NRTI) and two NRTIs for the management of HIV infection (Sterne, Heman, Ledergerber, Tilling, Weber, Sendi, Rickenbach, Robins & Egger 2005:378). ART is also sometimes regarded as a synonym for the term "HAART", which is an acronym for the words "highly active antiretroviral treatment" (Webster's Online Dictionary 2009a:[1]).

Antiretroviral drugs (ARVs) are medications that are used in the treatment of retrovirus infections such as HIV. ARVs target viral enzymes, including reverse transcriptase and

protease, which are pivotal in the lifecycle of the HIV virus and which have been proven to be effective in reducing the extremely high levels of morbidity and mortality that are caused by HIV/AIDS (Morris & Cilliers 2008:79). The objective of this kind of antiretroviral treatment is to reduce the HIV viral load in a patient's body to (if possible) undetectable levels, and thus to assist the person who is living with HIV/AIDS to regain health and to live a productive and healthy life (Amoroso et al. 2002:323).

For the purpose of this study, ARVs refer to the medications that are prescribed for HIV positive patients in terms of the protocols issued by the Ministry of Health in Uganda, which were based on the guidelines and recommendations of the WHO (WHO 2006b:11,17-64). In this study, the phrase *pre-free ART period/era* refers to the three-year period between July 2002 and June 2005 before the hospital in the study offered free antiretroviral treatment to HIV-infected members of the public in the Mpigi district. The phrase *post-free ART period/era* in this study refers to the three-year period between July 2005 to June 2008 after free access to ART was offered to the patients of the hospital under review with the support of the Ministry of Health of the Ugandan government and its development partners.

1.5.3 Cause of death

“Cause of death” is defined in Webster’s Dictionary (2009b:[1]) as “the causal agent resulting in death or factors which produce cessation of all vital bodily functions”.

In this study, the death refers to the clinical death of a patient that is characterised by the cessation of breathing and a detectable pulse rate or heartbeat and various other physiological signs of life. The cause of death may be attributed to the effects of disease or physical injury. These effects are documented in writing in the hospital records of the patient by the attending medical personnel as the primary or associated cause(s) of death. The leading causes of death in developing countries are infectious diseases.

1.5.4 The cluster differential 4 receptor

“The cluster differential 4” (CD4) is a glycoprotein that appears “on the surface of T helper cells, regulatory T cells, monocytes, macrophages, and dendritic cells” (Morris & Cilliers 2008:79). CD4 is the primary receptor that is used by HIV-1 viruses to gain entry

into host T cells. HIV as a retrovirus infects and replicates primarily in the cluster differential 4 plus (CD4+) T-cells and macrophages. The virus gains entry into the cell by attaching itself to the CD4 receptor. It then encodes the enzyme reverse transcriptase in such a way that this allows a DNA copy to be made from the viral RNA (Morris & Cilliers 2008:79.)

The CD4 cells are involved in coordinating and helping the immune response to proceed smoothly in protecting the body from infections (Gray 2008:123). Any disease such as an HIV infection that impedes or destroys CD4 cells causes the body's immune system to lose its ability to function, to become disorganised and to degenerate until it can no longer protect the body from alien invasive entities (Gray 2008:124).

1.5.5 Human immunodeficiency virus

“HIV” (also colloquially known as “the AIDS virus”) is a group of retroviruses that infect and destroy the helper T cells of the human immune system thus causing a significant reduction in their numbers – a deviation from their normal average number in the human body that is a diagnostic indicator of the disease AIDS (Webster's Online Dictionary with Multilingual Thesaurus Translation 2009:[1]). HIV is also defined as the agent that is responsible for the acute infectious manifestations, neurological disorders, and immunological abnormalities that are typical manifestations of the acquired immunodeficiency syndrome. HIV is a member of a group of viruses that belong to the primate-infecting lentiviruses of the family Retroviridae – which is why they are called “retroviruses” (Williamson & Martin 2008:109).

In this study, HIV is used as an acronym for the *human immunodeficiency virus* – the highly infective retrovirus that causes the most common form of acquired immunodeficiency.

1.5.6 Mortality

“Mortality” is defined in this study as “the ratio of deaths in an area [proportionate] to the population of that area; [it is] expressed per 1000 [members of a population] per year” (Webster's Online Dictionary 2009c:[1]). Mortality in this study refers to the “number,

magnitude or frequency of deaths over a period of time among the total sick and well population of an area” (Webster's Online Dictionary 2009c:[2]).

An “adult” in Uganda is defined in this study and by the Uganda Bureau of Statistics as an individual who is aged 15 years or older. “An adult death” therefore refers to the death of any person or individual who is 15 years or older (Uganda Bureau of Statistics, Government of Uganda 2006b:42).

This study focuses on the phenomenon of adult mortality in rural settings in Uganda, and is particular concerned with the incidence of hospital mortality or the death of individuals who are 15 years or older who died in a hospital setting during the study period.

1.5.7 Trend

A “trend” is defined as “long term movement in an ordered series” (Webster's Online Dictionary 2009d:[2]). In terms of this definition, a trend may therefore remain unchanged, or show an upwards or downwards movement. The word “trend” is used in this study to describe the monthly and annual frequency of adult deaths in a particular rural hospital in Uganda. This study identified and analysed the significance of trends in the hospital’s mortality rates during the pre-ART and post-ART era in order to determine the impact of ART on the overall mortality trends of the hospital.

1.5.8 Voluntary counselling and testing

“Voluntary” is defined as “proceeding from the will or from one's own choice or consent” (Merriam-Webster's Medical Dictionary 2009b:[1]). “Counselling” is defined the ability “to advise especially seriously and formally after consultation” (Merriam-Webster's Medical Dictionary 2009c:[1]). “Testing” can be defined as a diagnostic process and a “procedure for determining the presence or nature of a condition or disease”(Merriam-Webster Medical Dictionary 2009d:[1]).

Voluntary counselling and testing are the processes to which individuals or couples subject themselves when they undergo pre-test (“before the test”) counselling, the assessment of risks, the HIV test itself, and post-test (“after the test”) HIV prevention counselling.

For the purpose of this study, voluntary counselling and testing are the processes that are used when individuals or a couple agree to subject themselves (under the guidance of health care professionals) to a pre-test counselling session, to the collection of a sample of their body fluid (blood) for the purpose of HIV testing, and to participation in a post-counselling session after the results of the test(s) have been made known to them.

1.6 SIGNIFICANCE OF THE STUDY

The significance of this study is that it has, by following widely standardised procedures for scientific research, produced a new understanding of mortality trends in settings where HIV/AIDS are widely prevalent. It also sets out to demonstrate how these trends were affected by the provision of free access to ARV treatment. The results of the study will enable programme managers to design evidence-based interventions to reduce the magnitude of HIV-related mortality and thus overall mortality rates in general in hospital settings such as the one in which this study was undertaken.

Since the results of this study are not generalisable to the mortality trends in all rural hospitals across Uganda, this might be regarded as one of the limitations of this study. In spite of this, the study describes the dynamics of infection, treatment and mortality in Mpigi district and Mawokota South health sub-district – districts that are similar in many ways to other rural areas of Uganda.

1.7 DEMARCATION OF THE FIELD OF STUDY

The demarcation of the study field provided a framework within which the research took place, and the objectives of the study demarcated the problems and issues that needed to be included in the study and those that needed to be excluded from the research (Struwig & Stead 2001:44).

The study took place in a private not-for-profit hospital that is situated in Mpigi district of Uganda. It was selected by the researcher because he was able to determine from the hospital's records that the hospital had admitted a significant number of people who were HIV-positive, and that it had consequently been compelled to deal with a very large number of AIDS-related deaths over the years. Another factor that made the hospital ideal for this research was that it had been providing free ART to HIV-positive

patients for more than three years prior to the commencement of the study. This coincidental factor provided the researcher with an ideal opportunity to compare the mortality trends in the three years preceding the provision of free ART with the mortality trends in the three years after free ART had become available to patients.

The hospital in which this research was undertaken was a 100-bed private (not-for-profit) hospital that charged a fee for all patients who were admitted for treatment. The hospital served as the health sub-district headquarters for Mawokota South, an area that is located in the Mpigi district and that had a projected catchment population of 99 607 – 50 401 of whom were adults (i.e. who were 15 years or older in terms of the Ugandan government's official definition of "adult") (Lumala 2008:5,10). The hospital is supported by means of (1) grants from the government of Uganda (these are called "delegated funds"), (2) other funds obtained from bilateral donor arrangements, (3) privately allocated funds, and (3) other revenues (such as user charges) generated by the hospital (Lumala 2008:5). This hospital was also selected by the researcher because it was accessible, because the costs involved in the process of data collection were affordable, and because the process of data collection could be accomplished by the researcher in a shorter time than would have been possible in other hospitals.

The study focused on hospital mortality trends among all admitted individuals who were 15 years and older at the time of admission, over a period of six years. All pregnancy-related deaths and any other deaths that occurred before admission to the hospital were excluded from the study. The researcher reviewed all the case notes that described the circumstances of the patients' deaths that occurred during the study period. All in all, the researcher reviewed a total of 561 case files for the purposes of this study.

Since the Ugandan government had been providing free ART to health care facilities, there was a prevalent assumption that the affected patients were following the recommendations of the medical staff by accessing free ART early after they had been diagnosed as HIV-positive. ("Early" here refers to the period before the onset of advanced AIDS and the appearance of any of the large number of illnesses or conditions that are associated with full-blown AIDS.) If patients were, in fact, doing this, they would have been able to avoid the severely compromising health conditions that eventually result in death for those who are infected with HIV. For the past two decades, HIV had been the leading cause of morbidity and mortality in Uganda, and the provision

of free ART and public education about HIV/AIDS is expected to have been able to reduce the incidence of the long-standing effects of untreated HIV infection and the inevitability of the mortality rates that follow from such a condition.

This study therefore focused on the impact that free access to ART in the hospital setting made on mortality trends in the rural setting in which the hospital operated.

1.8 RESEARCH METHODOLOGY

Bowling (2002:143) defines *research methodology* as the practices and techniques that are used to collect, process and analyse data. Struwig and Stead (2001:44) also define research methodology as the collection and analysis of information in a way that will solve a problem, assist in the interpretation of a problem, or that will confirm or refute a specific hypothesis. The research methodology presents in specific terms the scientific method and procedures that the researcher will use to gather and analyse information. Included in the ambit of research methodology is the determination of sample size, the methods that the researcher uses to obtain a suitable sample, the way in which the researcher collects the data (such methods may include, for example, structured questionnaires, interviews and the examination and analysis of documents and historical records), the choice of measuring instruments, and clear explanations of how the researcher proposes to process and analyse the data (Bowling 2002:143).

The definition in the previous paragraph indicates that research methodology includes the research design, the study population, the sample variables (which referred to the characteristics of the individuals in the chosen population), their status (in so far as this is important), their relationships with one another, the instruments that are used for data collection, and the procedures that the researcher uses for data analysis (WHO 2001:11). Van Wyk (2005:728) notes that the term *research methodology* includes the essentials of research methodology, information about the questionnaires that are used, the size of the sample, the techniques of analysis, the types and sources of data, and the methods that are used in the analysis of the data. There is also importance in dating the various phases of the research such as the beginning and completion of all the major steps involved. This sets the research in a time framework that enables the reader to make sense of the methodology and the results (Van Wyk 2005:728). Since the research methodology thus frames all the activities that contribute to the success of

the research, the researcher has to make very careful decisions about the best ways to accomplish the research objectives.

This chapter only provided a brief introduction to the question of research methodology. This topic will be discussed in much greater detail in chapter 3, which contains a comprehensive description of the research methodology the researcher applied in order to accomplish this study.

1.8.1 Research design

A “research design” has been defined as “the overall structure or plan of a research activity” (Bowling 2002:143). A research design is, in other words, “a summary or a master plan to be followed to realize the research objectives or hypothesis” (Van Wyk 2005:82). The research design specifies the methods and procedures that were used for collecting and analysing the required information. A research design may be descriptive, exploratory or causal in nature (Van Wyk 2005:83).

The researcher opted for a quantitative, retrospective, descriptive and cross-sectional research design approach for this study. By using this particular approach, the researcher was able to provide a detailed description of the significance of the adult mortality trends before and after the introduction of free antiretroviral therapy in the particular rural hospital in Uganda that he had selected for this research.

1.8.1.1 Quantitative research

The research method that is used in a *descriptive design* is structured and quantitative in nature (Van Wyk 2005:86). *Quantitative research* consists of a formal, objective and systematic process for generating information. In quantitative research, a researcher connects evidence according to a carefully predetermined plan under rigorous and controlled circumstances, and uses formal instruments to collect the required quantitative information (Somekh & Lewin 2006:215). Quantitative methodology focuses particularly on the collection of quantitative and numeric data. In this way, it is very different from a qualitative methodology, in which quantitative and numeric data play a minor (if any) role.

In other words, a quantitative methodology makes use of quantities and numbers in order to describe relationships between predetermined attributes, and it involves the collection and analysis of numerically or quantitatively structured data (Bowling 2002:194). According to Van Wyk (2005:89), “quantitative research involves the collection of primary [numeric] data from large numbers of individuals with the intention of projecting the results to wider populations” in comparable circumstances. The aim of quantitative research is to be able to generalize about a specific population and to project its findings onto other populations that are similar in every respect to the experimental population that was involved in the original research. The data collected in quantitative research is then subjected to mathematical or statistical manipulation to produce conclusions that are broadly representative of the total population and forecasts of the probable course of future events under different but essentially similar conditions (Van Wyk 2005:89). Quantitative data consists of numerical data that is gathered by means of counting or measurement (Bland 1995:46).

In this study, the researcher collected quantitative data by using structured data collection tools that are known as audit tools. After the data had been collected, he was able to analyse the relationships between various attributes and variables, and make a number of interpretations that he subsequently used to inform the discussion and recommendations.

1.8.1.2 *Retrospective aspect of the study*

The retrospective aspect of a study design refers to the collection of information that describes events that occurred in the past (Bowling 2002:195,197). In this study, the researcher transcribed data that he collected from the case files of patients who had died in the period between June 2002 and June 2008. The collection of information about events that have already occurred in the past thus refers to the retrospective aspect of the study.

1.8.1.3 *The descriptive aspect of the study*

Bowling (2002:195) referred to descriptive surveys as information that has been collected from a sample of the population. This kind of information can be analysed and interpreted to provide answers in terms of descriptive statements and measures.

Descriptive research is designed to answer “who, what, when, and how questions” (Van Wyk 2005:86). Beaglehole, Bonita and Kjellstrom (2000:30) note that descriptive studies often constitute the first step in an epidemiological investigation. Descriptive research identifies and analyses the significance of various human activities, events and attitudes in such a way that they are able to shed light on the meaning of certain phenomena that occur in the population of interest. It is therefore typical of descriptive research that it examines the prevalence and extent of certain prevalent conditions. In descriptive surveys, phenomena are observed rather than tested. Descriptive studies literally *describe* the phenomena of interest as thoroughly and meticulously as possible. It also brings together into a coherent whole the various associations between variables so that a researcher is able to estimate certain population parameters for testing and generating hypotheses (Beaglehole et al. 1993:30; Bowling 2002:196).

In this study, the researcher collected information about mortality trends and other related data from all the death records of individuals who were 15 years or older in the selected rural hospital in the Mpigi district of Uganda at the time of their demise. He then analysed this information in order to arrive at an understanding of the effects of free access to ARV medications for the HIV-positive patients who were receiving therapy and treatment in the Mpigi rural setting.

1.8.1.4 *The cross-sectional nature of this study*

Cross-sectional studies entail the collection of data from a cross-section of a population. The cross-section may be taken from the whole population or from a proportion (sample) of it (WHO 2001:17).

In this study, morbidity and mortality rates in a rural setting were the focus of investigation. Because the mortality records of deaths that have occurred in home settings are usually never reported in any statistical record systems and because such deaths constitute a significant proportion of all the deaths in rural settings in Uganda, a cross-section of the deaths that occurred in the hospital were considered to be a proxy measure of mortality trends that were more or less representative of a number of deaths in rural settings in Uganda.

1.8.2 Research methods

The *research method* serves as the rationale for research, and it also articulates the criteria that are used for interpreting data (Burns & Grove 2001:223). In this section, the researcher describes the study population, the method of sampling, the sample itself, the method of data collection and the method that he used for data analysis.

1.8.2.1 Population and sample

The *population* in a study includes all the elements (which might be either objects or people) that meet the criteria that make them typical of a particular population (Burns & Grove 2001:47). Polit and Beck (2006:259) describe a population as “the entire aggregation of cases that meet the” requirements of specified criteria. The population represents the entire set of individuals (either human beings or objects) that have common characteristics. The *accessible population* comprises those individuals who conform to the eligibility criteria and who are available for participation in a particular study, whether directly or from the evidence of the records of their experiences in the hospital (Burns & Grove 2005:342).

In this study, the population consisted of all the individuals who had died in a selected hospital in the Mpigi district of Uganda.

A *sample* can be defined as a subset of a population that is selected to participate in a study (Polit & Beck 2006:260). A *convenient sample* consists of the most readily available or most convenient group from a particular sample (Cohen, Manion & Morrison 2000:102). The researcher chose this method because it enabled him to gain ready access to the hospital files of the deceased.

The sample that was selected for this study included all those adult individuals who had been admitted to the medical and surgical wards in the hospital, and had subsequently died in the hospital. Because of the relatively low incidence of deaths in rural hospitals, the researcher included all adult hospital deaths of patients who had been admitted to hospital during the study period. The eligibility criteria were therefore fixed as follows:

- (1) The cases that were used in the study included all adult hospital deaths (i.e. only those individuals who were 15 years or older when they died were included in the data).
- (2) All the patients were included for the collection of data had died in the medical and surgical wards of the hospital in the period between June 2002 and June 2008.

The researcher fixed the exclusion criteria as follows: (1) All maternal- or obstetric-related deaths, (2) All deaths that had occurred *before* admission, and all dead bodies that had been admitted to the hospital for post-mortems or autopsies were also excluded from the sample. The researcher identified the study population from by examining the hospital patient records (such records included death certificates, hospital inpatient case notes and registers).

Sampling can be defined as the process of selecting a portion (component) of the population that is representative of the entire population. The elements that are selected are then referred to as the *sample* (Polit & Beck 2004:291.) According to Bryman (2004:87), a sample has to be representative of the population it purports to represent if one wants to be able to make generalizations about the findings from the sample to any wider and similar populations.

Sample size refers to the number of elements that are included in the sample. Brink, Van der Walt and Van Rensburg (2006:135) and De Vos, Strydom, Fouche and Delpont (2002) suggest that “a study with an over-large sample may be deemed overly sensitive”. A large sample is therefore no guarantee of an increased degree of accuracy in the findings (Brink et al. 2006:136). The sample size for this study consisted of 561 patient records of deaths that occurred between June 2002 and June 2008.

1.8.2.2 Data collection

Burns and Grove (2001:49) defined *data collection* as “the precise systematic gathering of information relevant to specific research objectives or questions”. In this study, the researcher collected data by using two (tools A and B), both of which were structured audit tools.

In order to place himself in a situation in which he could compile a case-by-case summary, the researcher designed a data collection called tool A, which consisted of four sections:

- Section 1: This section reflected the individual's demographic profile, and it included the hospital or in-patient number, the hospital ward, the sub-county of the patient's home location, the patient's date of birth, and the patient's recorded age at the time of admission and death.
- Section 2: This section consisted of the record of the patient's last visit, including the date of admission, the date of death, the diagnosis upon admission, the recorded cause of death and the associated causes of death.
- Section 3: This section consisted of recorded information from the patient's record that related to his/her HIV infection status, and it included the following: the patient's HIV status, his/her history of ART participation, the date when ART commenced, and the assumed causes and evidence for the causes of death as recorded in the records.
- Section 4: The last section consisted of endorsements by the research assistant.

After the data collections tools had been pre-tested, they were thereafter used for data collection. On the basis of diagnosis and the cause of death, all deaths were classified as being either HIV-related or non-HIV-related – or “undetermined”. All this data was compiled by making use of this structured audit tool (data collection instrument), and the data collection process entailed the scrutiny of all patient records during the audit or review of the patients' records. Data collection tool A collected information about the following features: the age of the patient at time of death, the patient's gender, the hospital ward, the date of admission, the date of death, the cause(s) of death, the primary cause of death, the associated cause(s) of death, the HIV status of the patient (if indicated in the records), and the patient's history of participation in ART treatment.

The researcher also designed data collection tool B specifically for this study so that he would be able to compile summaries of the statistics in the medical records department about overall mortality and morbidity parameters. This information was used to enhance the analysis of mortality trends. The second Audit tool (which was referred to as tool B) consisted of the following three sections that summarised the following information:

- Section 1: Hospital name, district, date of data collection.
- Section 2: A month-by-month summary of the number of adult admissions, the number of patients on ART, the number of new patients started on ART, the total number of all deaths of individuals of less than 15 years old, and the total number

of deaths of all individuals of 15 years and older that were documented in the hospital records during the study period.

- Section 3: Records of the medicines and drugs in the hospital on a monthly basis, the number of days when the hospital had no stock of the five ARV medicines in hand that are indispensable for the treatment of HIV patients in the hospital (these essential ARVs included Lamivudine, Stavudine, Efavirenz, Zidovudine, Nevirapine – and combinations of these medicines).

The researcher used data collection tool B to collect data about all adult admissions to the hospital, the cumulative number of patients who were on ART at any given time, and the overall number of deaths that were certified by the hospital's medical staff.

For the purpose of this study, the data was collected over a period of four weeks in December 2008.

1.8.2.3 Data analysis

The data was carefully scrutinised for accuracy before it was entered into the Epi Info database. The researcher performed the data analysis with assistance from a colleague with extensive statistical skills by using the Epi Info (Version 3.5.1, August 2008) and the Statistical Package for the Social Sciences (SPSS version 12). Frequencies were determined for the responses to all the items in the audit, and this information was used in the results section as a basis for discussion and the reaching of conclusions. Bivariate analysis was carried out and categorical variables that were in three or more levels were re-categorised into two and analysed by use of two by two dummy tables. The results were presented in terms of prevalence proportion ratios (PPR). All factors with significant odds ratio ($p < 0.05$) in the bivariate analysis were included in the subsequent discussion. Chi-square statistics were also conducted on those variables that demonstrated a high statistical significance of association with hospital mortality rates.

This study also made use of the technique of trend analysis. Statistical trend analysis provide “an indication of the underlying movement of a statistical series. Trends can be used to get a general impression of the underlying behaviour of a variety of series” (Office of National Statistics 2008:[1,2]). The trend analysis enabled the researcher to

understand the significance of the course of events that characterised the delivery of ART in the hospital under study.

The remainder of the trend data was compiled and presented as trends that occurred over time in line graphs. Trend studies are appropriate for assessing change over periods of time because variables are measured on more than one occasion (Office of National Statistics 2008:[1,2]).

1.9 VALIDITY AND RELIABILITY OF THIS STUDY

1.9.1 Validity

“Validity refers to whether or not the measurement collects the data required to answer research questions” (Somekh & Lewin 2005:216). Content-related validity is defined by Burns and Grove (2001:400) as “the extent to which the method of measurement includes all the major elements relevant to the concept being measured”. These authors add that it is useful for a researcher to cite sources from the literature in order to create a synthesis that will enable a more accurate understanding of the phenomenon under study.

In this study, two consultants reviewed the research tool for clarity and content, after which certain identified items that had been omitted or unclear were added for purposes of clarification.

The internal validity was also enhanced by the structured nature of the data collection method, by the careful training of the data collection assistants, by triangulating data from a wide variety of hospital records that included ward registers, patients’ case files, death certificates, and by cross-checking information with health workers. Internal validity was also enhanced by random verification of the completed data collection tools by the researcher on a sample of records that had been completed by the research assistants so that he would be in a position to determine the completeness and accuracy of the information that had been collected.

1.9.2 Reliability

Reliability also refers “to the stability or consistency of measurements; that is whether or not the same results would be achieved if the test or measure was applied repeatedly” (Somekh & Lewin 2005:216). In this study, reliability was enhanced by a structured data collection tool that the researcher had developed on the basis of the research objectives and had pre-tested to ensure that the tools were able to measure the key variables of the study accurately and as comprehensively as possible. The data collection method therefore consisted essentially of a process whereby the researcher and his research assistants retrieved the required information about the frequency distribution of hospital deaths from the hospital’s records by using a custom-made structured audit tool.

1.10 ETHICAL CONSIDERATIONS

The most important ethical requirement for the research included carrying out the research competently, managing the resources honestly, acknowledging the role of those who contributed guidance and assistance, the accurate and unbiased communication of results, and a careful consideration of the impact that the research would make on society in general (Brink et al. 2006:30).

Since this study focussed on the medical records of deceased patients, an attitude and principle of respect was maintained through unconditional participation in the study by the district authorities and the hospital management (Brink et al. 2006:32). Participation in this study entailed no risks, penalties or prejudicial treatment, and the members of the hospital’s management were informed that they had an unequivocal right to withdraw from the study at any time without incurring any prejudice or penalty, and that they also had the right to ask for whatever clarification they needed about the purpose of the study (Brink et al. 2006:32).

The information that was collected was treated as entirely confidential, and it was never made available to any unauthorised individuals who were not directly involved in the study. Throughout the course of this study, the researcher adhered to the principles of voluntary participation, confidentiality, informed consent, the minimisation of harm, and the anonymity of the deceased patients whose records supplied the necessary data.

The researcher trained the data collection assistants to maintain the confidentiality of the patient records with the utmost strictness, and they only used the data collection tool to extract the required information from the hospital's patient records. The data collection assistants worked under the supervision of the records section staff of the hospital. No patient file was ever removed from the hospital's records department, and all files were returned to the shelves from which they had been collected when the required information had been recorded.

1.11 LIMITATIONS OF THE STUDY

Despite the extensive efforts that the researcher made to eliminate and minimise errors by using a structured audit tool and by carefully training the research assistants, the information obtained from a number of the medical records was incomplete. The incompleteness of the records made the process of data collection to some extent vulnerable to researcher biases – especially in those cases where diagnoses had not been not well written or in cases where the information contained in the records was incomplete or absent.

Where inconsistencies and inadequacies in data were identified, the records were verified (wherever possible) with the responsible health care workers. An agreement about how to treat missing information was reached through the triangulation of records. This enhanced the possibility that missing information could still be accurately compiled by the data collection tool. In cases where all these measures were not able to produce a plausible rendition of missing all fragmentary information, the cases concerned were identified as incomplete and the data that had been obtained from them was not included in the analysis.

1.12 LAYOUT OF THE STUDY

This dissertation consists of the following six chapters:

Chapter 1: This chapter introduces the study area, the research problem, the purpose of the study, the objectives and research design, the methodology that the researcher utilised in the study, and the definition of key terms.

Chapter 2: This chapter contains the literature review.

Chapter 3: This chapter discusses the research design and method.

Chapter 4: This chapter presents the findings, analysis and the interpretation of the results.

Chapter 5: This chapter discusses the conclusions and limitations of the study, and makes various recommendations for practice and further research.

1.13 CONCLUSION

This chapter described the background in context of the study, the profile of the country in which the research took place, a brief description of the Mpigi district of Uganda, the research problem, and the research questions. Chapter 1 also discussed the purpose of the study, its objectives and assumptions, the demarcation of the field of study, the research design and method, and the general layout of the study.

Chapter 2 will present the literature review that informs the research.

CHAPTER 2

Literature review

2.1 INTRODUCTION

In order to provide an authoritative understanding of HIV/AIDS situation globally and specifically in sub-Saharan Africa, the researcher undertook a comprehensive review of the literature on the subject. This chapter therefore contains a detailed review of the existing literature about the key concepts and issues that constitute the basis of this study. Because such an enormous amount of literature and research already exists on this subject, the researcher approached the literature study in a systematic and selective manner that illuminated his specific research interests. By doing this, he excluded all references to topics in the literature that were irrelevant or marginal to his central thesis.

It is the purpose of a literature review to critically examine and discuss the research that has already been undertaken and documented on a particular topic. The researcher therefore located, analyzed, synthesised and interpreted all the previous research and documents (such as periodicals, books and abstracts) that related to the topic of his study. According to Roberts (2004:73), a literature review serves the following purposes:

- It helps to bring a study into proper focus by relating it to what is already known about the topic.
- It identifies key variables for research and suggests the relationships that might obtain among them. It also provides suggestions about how previous research on the topic could be usefully extended by means of further research and study.
- It identifies the exact way in which the study topic relates to present and past studies and findings.
- It also provides a basis for determining the significance of the study.
- It helps a researcher to make strong logical and contextual links between the findings and procedures of the present study and all previous studies in the field.

The literature review of the study also enabled the researcher to achieve a more refined and in-depth understanding of the intricacies of HIV disease, and it revealed a wealth of additional information about morbidity and mortality trends in the Western (developed) world and in the context and settings of developing countries such as those of sub-Saharan Africa. The researcher also reviewed and assessed the methodology, instruments, findings, conclusions and limitations of different studies. By carrying out a literature review of this kind, the researcher familiarized himself with current trends, developments and achievements in reducing morbidity and mortality in high and low HIV prevalence settings. This gave him the information that he needed to make clear, authoritative and meaningful comparisons between the two settings mentioned above.

The researcher also made use of the literature review to document the socio-demographic impact of HIV/AIDS. It also placed him in a position to describe the significance of the present study to HIV/AIDS programme managers, district health and hospital managers. After he had identified and examined a variety of approaches and all available data about trends, he then reviewed information that he had acquired and formed the basis for selecting the study population and the site in which the study would take place. He also summarised whatever critical information was relevant to this study so that his understanding of the research question would be refined and enhanced. As a result of this approach, the researcher was able to define three scenarios to describe expected trends in this field and to identify the most important lacunae in current HIV/AIDS research (especially as it applies to the countries of sub-Saharan Africa). These scenarios provided a researcher with a basis for reaching conclusions about the central research questions of the study.

This literature review captured documented comparative experiences in both developed and developing (resource-constrained) settings are not concerned with the details of protocols of HIV morbidity and treatment but in the overall effect of interventions. The review took into account the enormous impact that ART has made to different aspects of HIV/AIDS morbidity and mortality. It has also increased the prevalent understanding of the morbidity and mortality rates in the pre-ART and post-ART eras.

The researcher carried out a comprehensive online search of medical bibliographical databases and journals by making use of the following subject headings: HIV/AIDS, ART, hospital mortality, hospital morbidity, sub-Saharan Africa, Mpigi district and

Uganda. While the literature review mainly covered the ten-year period between 1998 and 2009, it also incorporated a few references to the period before 1998 because of their specific relevance to the topic of this research.

The references that were identified are contained in journal articles, books, reports and websites. This enabled the researcher to compile a comprehensive and relevant literature review. Because this section offers the reader an in-depth understanding many of the intricacies of the current state of knowledge about HIV/AIDS, it also provides a basis for the discussions that follow and the conclusions of the study.

2.2 HUMAN IMMUNODEFICIENCY VIRUS DISEASE

This section provides a brief overview of the HIV that includes information about the origins of the virus, the historical background of the epidemic, and the distinctive characteristics of the HIV virus. It also includes the ways in which it operates in the human body, and the means by which it is transferred from one human being to another.

2.2.1 Origins of the human immunodeficiency virus

The origins of HIV have been the subject of numerous theories and a great deal of speculation. Although any detailed discussion about the origin of HIV is beyond the scope of this study, one theory is discussed here because it provides a feasible hypothesis about the origins of HIV. Some researchers have discussed the probability and likelihood that HIV originated from an ancestral HIV-1 M virus that was transmitted (by means that as yet unknown) from chimpanzees to human beings in equatorial West Africa as long ago as during the 1930s (Williamson & Martin 2008:109).

The first documented case of HIV-1 was positively identified in the human being from a blood sample that was taken in 1959 from a man in Kinshasa in the Democratic Republic of the Congo. While the particular way in which this first documented case of HIV infection became infected is unfortunately unknown, a genetic evaluation of this blood sample dates the origin of this form of HIV-1 to the late 1940s or even the early 1950s (CDC 2009:[1].)

Because of host selection pressure, the HIV virus has proliferated its genetic diversity by subdividing into a number of closely related subtypes (Essex & Mboup 2002:4). It is this capacity of HIV to mutate into forms of “extreme genetic diversity that is a consequence of the error-prone and recombinogenic nature of HIV replication [which] seriously threatens our chances of containing the [HIV] AIDS epidemic” (Williamson & Martin 2008:109).

2.2.2 Historical overview of the epidemic

HIV/AIDS was first positively identified in the United States of America in 1981 as a new and apparently highly lethal disease that was initially thought to infect only homosexual men (Essex & Mboup 2002:1). Subsequent to this discovery, the term “AIDS” was first coined in 1982 to describe the syndrome of opportunistic infections that caused rapid sequences of deterioration in the health status of previously healthy people. It was in the same year (1982) that the health authorities in the United States began their formal tracking (surveillance and monitoring) of HIV and AIDS wherever and whenever it appeared. It was in 1983 that the virus that causes AIDS was first positively identified and described (CDC 2009:[1].) Soon after this discovery and description of AIDS and HIV, the disease began to be reported in other parts of the United States of America and also in different parts of the world, including Europe and Africa (Essex & Mboup 2002:1).

Ever since the discovery of HIV in the early 1980s, the number of people who have been infected and who are currently living with HIV increased exponentially from a mere handful to more than 40 million cases. More than 20 million of these people have already died from the effects of AIDS-related illnesses and conditions (Abdool Karim 2008:31). In sub-Saharan Africa, the spread and course of the HIV/AIDS epidemic has varied from country to country and from region to region, and has displayed a variety of patterns of diffusion in rural and urban settings and made an enormous impact on the lives of those who are infected and the societies in which these infections occur.

In Uganda, for example, the prevalence of HIV has been reduced from 23.2% in 1989 to 11.8% in 1995, to 5.2% in 2000, and to 7.1% in 2007 (Ministry of Health – Government of Uganda 2009:14). But in South Africa, in contrast, the HIV/AIDS epidemic has been characterised by an “*explosive*’ spread with no sign of a ‘saturation’ plateau and

predominance in women at [a] younger age” (Abdool Karim & Abdool Karim 2002:38). The spread of the virus in South Africa has been characterised by a rapid rise in HIV prevalence from 0.8% in 1990 to 10.4% in 1995 and 22.4% in 2000, and a concomitantly high mortality rate. In South Africa, 40% or more of all adult deaths are attributed to the effects of AIDS (Abdool Karim & Abdool Karim 2002:39).

These two patterns of diffusion and infection in Uganda and South Africa describe the variability of the impact of HIV/AIDS in two countries in the same sub-region of the world called sub-Saharan Africa.

2.2.3 Characteristics of the human immunodeficiency virus

HIV is the infective agent that compromises the immune system of the human body to certain extent that it becomes defenceless against the various opportunistic diseases that ultimately collectively culminate in a syndrome colloquially known as AIDS. This disease is called **acquired** because it is not genetically inherited but is caused by a viral infection. A *deficiency* is a shortcoming which, in this context, refers to the way in which the HIV weakens the immune system and so makes the body unable to defend itself against infections and diseases (Van Dyk 2005:3). Some of these opportunistic infections (such as tuberculosis) to which the infected person becomes vulnerable tend to occur in the combination with a variety of other health defects in the patient in such a way that an untreated patient is soon overwhelmed by the burden of morbidity and succumbs to death.

Van Dyk (2005:4) therefore describes AIDS as a “collection of many different conditions that manifest in the body (or specific parts of the body) because the HIV has so weakened the body’s immune system that it can no longer fight [the] disease-causing agents that are constantly attacking it”. Van Dyk (2005:4) further describes AIDS as “a syndrome of opportunistic diseases, infections and certain cancers – each or all of which has the ability to kill the infected person in the final stages of the disease”. This is the ultimate fate for HIV-infected human beings who do not enjoy the privilege of treatment or whose health status has so deteriorated that there are no longer amenable to the benefits of modern antiviral therapeutic medications.

2.2.3.1 The nature of the human immunodeficiency virus

The HIV virus is a member of the group of viruses referred to as the primate infecting lentiviruses of the family Retroviridae (thus called retroviruses) (Williamson & Martin 2008:109). A virus is an extremely small parasitic organism that hijacks the naturally occurring biochemical facilities of living cells (such as human cells) to reproduce itself in a manner that allows it to spread rapidly until it pervades the whole human body (Van Dyk 2005:9). Viruses contain all the genes that are necessary for their replication in form of deoxyribonucleic acid (DNA) in their cores (Van Dyk 2005:9). But some viruses have cores that contain ribonucleic acid (RNA) rather than DNA, and this class of viruses are therefore called *retroviruses* (Van Dyk 2005:9).

RNA is characterised by the fact that it is single-stranded while DNA is characterised by the fact that it is double-stranded. The RNA nucleotides (like the ones of the HIV) contain ribose while DNA contains deoxyribose, and RNA contains uracil compared to DNA that contains thymine (Essex & Mboup 2002:1-3). HIV is therefore classified among the retroviruses because its genomes contain RNA and their ability to mutate is dependent upon the use of an RNA template that utilises the enzyme *reverse transcriptase* (Essex & Mboup 2002:1-3; Morris & Cilliers 2008:80). A more detailed description of DNA and RNA is beyond the scope of this study. What is relevant to this discussion is the HIV-1 genome that is depicted in figure 2.1.

2.2.3.2 The human immunodeficiency virus genome

The HIV genome consists of HIV-specific proteins, which are indicated by the colours pink and purple in figure 2.1, and all the other elements that are common to retroviruses.

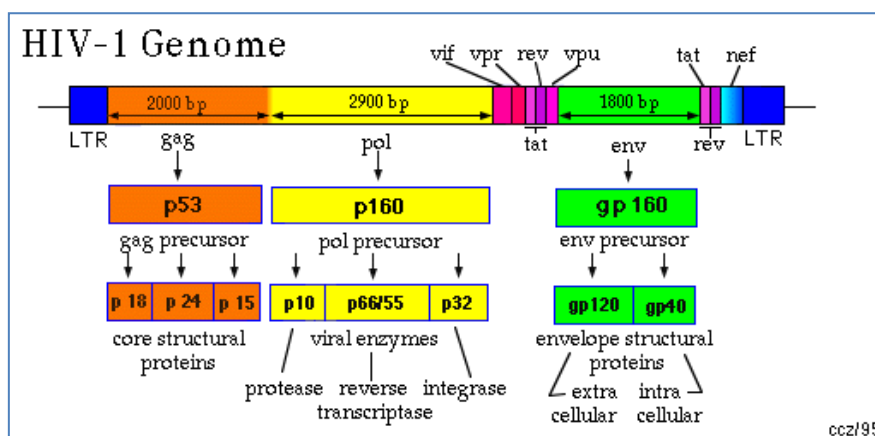


Figure 2.1: The Human Immunodeficiency Virus genome

(Source: HIV Laboratory – Yale University 1998:[1])

Key to the abbreviations used in descriptions of the HIV-1 virus:

LTR – long terminal repeats; repetitive sequence of bases

gag – group specific antigen gene, p24, a nucleoid shell protein

pol – polymerase gene; encodes the viral enzyme, protease (p10), reverse transcriptase (p66/55); and integrase (p32)

env – envelope gene; encodes the viral envelope glycoproteins gp120 (extracellular glycoprotein, and gp41 (transmembrane glycoprotein)

tat – encodes transactivator protein

rev – encodes a regulator of expression of viral protein

vif – associated with viral infectivity

vpu – encodes viral protein U

vpr – encode viral protein R

nef – encodes a “so-called” negative regulator protein

Of special interest are the gag, pol and the env sections (see Figure 2.1), which encode the nucleocapsid, polymerase, and envelope proteins respectively. These sections of the virus are all critical for the replication of the HIV and are crucial for the diagnosis and management of the infection. The polymerase section of the genome consists of the protease enzyme (p10), reverse transcriptase enzyme (p66/55) and the intergrase enzyme (p32). These three enzymes are indispensable for the ability of the HIV to replicate itself (see figure 2.2). These three enzymes are therefore specifically targeted by ARVs because they have the ability to prevent the HIV from replicating itself (see section 2.3.1 for further information about this process).

HIV is categorised into two types, namely HIV-1 and HIV-2. (AIDS Information Switzerland 2009:[3]; Essex, Mboup, Kanki, Marlink & Tlou 2002:4). HIV-1 is far more virulent and aggressive (pathogenic) virus than the HIV-2 virus (Van Dyk 2005:20). HIV-1 exists in three lineages that had been labelled as the M, N and O groups respectively, and they are widely prevalent in East and Southern Africa. The HIV-2 is found in the lineages that have been labelled as the A, B and G groups, and these are most prevalent in West Africa (Essex & Mboup 2002:4; Williamson & Martin 2008:109). The viruses from the HIV-1 M group are primarily responsible for virulence of the global AIDS epidemic (Williamson & Martin 2008:109). The HIV-1 M lineage has been further subdivided into the subtypes A, B, C, D, F, G, H, J and K (Montano & Williamson 2002:11; Williamson & Martin 2008:110).

2.2.3.3 *The human immunodeficiency virus replication cycle*

Like other viruses, the HIV survives and replicates specifically in human body cells that are referred to as “host cells” (AIDS Information Switzerland 2009:[3]; Van Dyk 2005:10). HIV invades and replicates itself primarily in the CD4+ and T helper cells (Van Dyk 2005:9). When a HIV invades the host cells, it transforms the viral genetic material (RNA) into human genetic material (AIDS Information Switzerland 2009:[3]). In figure 2.2, step 2 shows how the HIV attaches itself to the CD4 receptor before it gains entry into a human cell (step 3). Once the virus has invaded a human cell, it then encodes the reverse transcriptase enzyme (step 4). The encoding of the reverse transcriptase enzyme enables the virus to make a DNA copy from its viral RNA (Morris & Cilliers 2008:79).

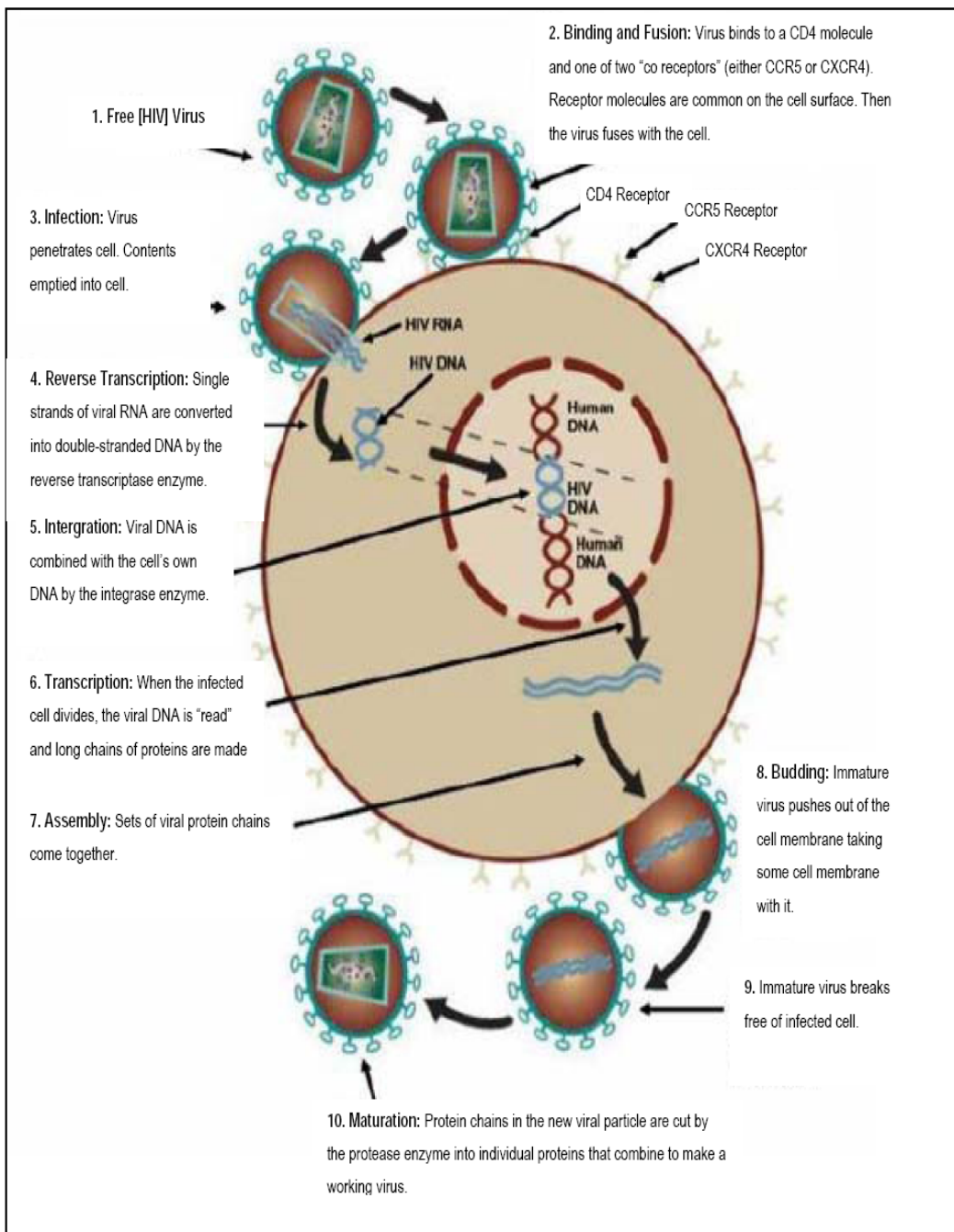


Figure 2.2: Graphic portrayal of the HIV replication cycle

(Source: Indian River State College 2008:[1])

In step 5 of the process of replication, the HIV DNA that has been formed combines with the DNA of human cells by making use of the enzyme integrase. Once the HIV has succeeded in inserting its genetic material into that of the host cell, it then proceeds to utilise the human cells that it has hijacked to replicate itself and form new virus components (AIDS Information Switzerland 2009:[3]). Step 6 shows how transcription occurs and how long chains of proteins are created that join together (step 7) to form an

immature virus that buds to the cell membrane (step 8) and eventually breaks through the wall of the host cell (step 9). By making use of the enzyme protease, the newly formed immature virus (now mature, as is illustrated in step 10), it attaches itself to new host cells and proceeds to infect those new cells, thereby initiating the whole cycle all over again (AIDS Information Switzerland 2009:[3]).

The CD4 cells are indispensable for coordinating the body's immune response against invasive infections and intrusive toxins (AIDS Information Switzerland 2009:[4]; Gray 2008:123; Van Dyk 2005:9). During the cycle of HIV replication, the CD4 cells of the body are systematically destroyed and this causes the human immune system to become progressively compromised, disorganised and degenerate until it can no longer perform the function for which it exists (Gray 2008:124). This cycle of destruction initiated by the HIV results in a progressive reduction of the body's average number of CD4 cells, and this in turn undermines the body's immune system until it is no longer capable of defending the body in a way in which it was designed to do (Zijenah & Katzenstein 2002:34). The ever-expanding number of human immunodeficiency viruses eventually makes the body's immune system so weak in the terminal phase of the disease that it becomes vulnerable to a great number of disease-causing agents that the immune system would normally be able to resist in its normal healthy state. This final concatenation of diseases and pathological conditions that ultimately cause the death of the patient is what is called "AIDS" (Van Dyk 2005:4). This progressive depletion of the normal number of CD4 cells and the eventual inability of the body to meet the demand of any kind of immune responses ultimately results in clinical disease and death (Zijenah & Katzenstein 2002:34). The HIV therefore acts as a catalyst, so to speak, of the acquired immune deficiency syndrome. It is therefore correct, but somewhat misleading without further amplification, to refer to HIV as a cause of mortality in patients whom it has infected.

It is important to realise that the virus has perfected a strategy to integrate itself into each individual healthy human cell and so transform those human cells into "factories" that become extremely efficient producers of large numbers of further viruses. In the process of making new virus particles, the cells of the human body and the receptors sites that are critical for the protection of the body are destroyed one by one, thus leaving the body vulnerable to a variety of disease-causing agents.

2.2.4 The transmission of the human immunodeficiency virus

HIV is transmitted from one HIV-infected person to people who are free of the virus by means that have now been well understood and described (AIDS Information Switzerland 2009:[6]). HIV transmission and infection occur when body fluids that contain the virus come into contact through microscopic cracks in the mucous membranes or the broken skin of the recipient. The virus can also directly enter the circulatory system by means of, for example, the use of HIV-infected needles that are shared between HIV-positive people and HIV-negative people (Morris & Cilliers 2008:85). While the virus is present in high concentrations in bodily fluids such as blood, semen and vaginal secretions, other human body fluids such as saliva, breast milk, tears and urine contain much lower concentrations of the virus and are therefore less infectious (AIDS Information Switzerland 2009:[6]). Most cases of transmission occur when those body fluids that contain very high concentrations of the virus such as sperm and vaginal secretions some way or the other enter the bloodstream of an HIV-negative person (Van Dyk 2005:23).

HIV is transmitted primarily through sexual intercourse because this enables HIV-infected body fluids to pass from the body of an infected person to another person or from a mother to her baby during pregnancy or childbirth. A baby can also become HIV-positive as a result of breast feeding from a mother who is HIV-positive (AIDS Information Switzerland 2009:[6]; Morris & Cilliers 2008:80; Van Dyk 2005:23;). Of the 3.7 million new HIV infections that currently exist throughout the world, an estimated 75% to 87% were acquired by means of heterosexual intercourse (Abdool Karim 2005:243; Kristensen, Sinkala & Vermund 2002:217).

HIV infection is therefore primarily a sexually transmitted infection and the main mode of HIV transmission is through unprotected sexual intercourse (intercourse that takes place without a condom), and through penetrative vaginal or anal sexual intercourse (AIDS Information Switzerland 2009:[6]; Van Dyk 2005:23). HIV is also transmitted when drug addicts who are accustomed to injecting themselves share HIV-contaminated syringes and needles (AIDS Information Switzerland 2009:[6]) and in low-resource settings where unsterilized needles have to be reused because sterile ones are unavailable.

HIV can also be transmitted through blood transfusions or the constituents of other blood products that contain HIV and through needle-stick injuries and bite wounds. HIV transmission also occurs in other incidences of skin-penetrative injuries such as those that are inflicted by traditional healers in some African societies to make traditional therapeutic skin markings on the skin of their clients (Kristensen et al. 2002:225; Van Dyk 2005:29.) There has been no documented and verified incidences of HIV transmission from everyday life activities such as contacts between the skin of the human buttocks and the seats of public toilets, casual (i.e. non-penetrative) skin contacts, kissing, hugging or the sharing of swimming bath water with people who are the HIV-infected (AIDS Information Switzerland 2009:[7]). There is also no evidence at all to suggest that HIV can be transmitted through airborne droplets as is the case with influenza. It is indeed fortunate for the human race that there is thus far no evidence that HIV can be transmitted by means of the microscopic droplets that are produced by coughing, and that it can only be transmitted from one person to another when the virus enters a non-infected person's blood stream from infectious body fluids into a healthy human body through the numerous but almost invisible cracks in the mucous membranes during the act of vaginal or anal sexual intercourse (Van Dyk 2005:24).

But there are several other factors that are thought to increase the risk of contracting HIV infection from infected people. These include being a person who has habitual contacts with multiple sex partners, the presence of sexually transmitted infections, high concentrations of the virus in the semen or vaginal fluids of an infected sex partner, and the occurrence of trauma during sex (Kristensen et al. 2002:219; Van Dyk 2005:27).

In sub-Saharan Africa (including Uganda), the main modes of HIV transmission is unprotected heterosexual intercourse. A much smaller number of infections is caused by the use of blood products not screened for HIV in blood transfusions and the use of HIV-contaminated needles (Benatar, Doherty, Heunis, McIntyre, Ngwena, Pelsler, Pretorius, Redelinghuys & Summerton 2004:277). Sub-Saharan Africa remains the region of the world in which the greatest number of infections occurred. In fact, an estimated 70% of all new HIV infections in the global AIDS epidemic occur in sub-Saharan Africa (Kristensen et al. 2002:217). In 2007, it was estimated that 1.7 million (i.e. between 1.4 million and 2.4 million) people had been newly infected with HIV, and that 68% of all these new HIV infections as well as 76% of all AIDS-related deaths had occurred in sub-Saharan Africa (UNAIDS & WHO 2007:15).

2.2.4.1 *The prevention of HIV infection*

Since there is no vaccine that will prevent a healthy person from contracting AIDS or any kind of curative treatment, the only way to prevent infection is to minimise the risk of being infected by means of sexual transmission. The best methods of preventing infection to date are abstinence, faithfulness to one uninfected sexual partner, and the use of condoms during sexual intercourse. If people who are sexually active, they should strive to be completely be faithful to one sexual partner and or always use condoms whenever they engage in casual sexual intercourse with anybody whose HIV sero-status is unknown to them (AIDS Information Switzerland 2009:[7].)

2.2.5 *The progression of the human immunodeficiency virus disease*

When an HIV-negative person is infected with the HIV, the viruses invade host cells and immediately begin to replicate themselves in human cells (see figure 2.2). This process leads to the rapid multiplication of the HIV which attacks and destroys its host cells by taking them over and making them into instruments for the replication of new versions of themselves. It is this process of viral multiplication and its consequent destruction of human cells that is the cause of HIV disease.

2.2.5.1 *The weakening and destruction of the immune system*

The human immune system performs two critical functions in the body. Firstly, it combats the infections caused by bacteria, viruses, fungi and parasitical agents. Secondly, the immune system prevents cancer by destroying the body's own damaged or deteriorated cells (AIDS Information Switzerland 2009:[3]; Van Dyk 2005:12-13).

During the acute infection phase, thousands of new viruses are formed, and the immune system responds to this by destroying as many viruses as it can (AIDS Information Switzerland 2009:[3]; Morris & Cilliers 2008:85). Thereafter, during the symptom-free latency phase (which is also known as stage I of the disease), HIV replicates millions of copies of itself. In the meantime, the body's immune system continues to destroy as many viruses as it can in order to maintain a balance between new and destroyed invading viruses. In the last stage of the infection (which is known as AIDS), the capacity of the human immune system has become exhausted and

uncoordinated, and it is unable to cope any longer with the overwhelming HIV load (or number of viruses present) within the body. With the progressive weakening of the immune system, the overall number of HIV steadily increase until the body becomes vulnerable to all kinds of infectious diseases and various forms of cancer (AIDS Information Switzerland 2009:[3].)

The kind of infections that occur when the body's immune systems is compromised are called "opportunistic infections", and they contribute significantly to the mortality and morbidity experienced by people who are living with HIV/AIDS. It is reported that the development of opportunistic infections such as pulmonary tuberculosis, oropharyngeal candidiasis and Pneumocystis Carinii pneumonia, is associated with radically decreased rates of survival in patients (Kumarasamy, Solomon, Flanigan, Hemelatha, Thyagarajan & Mayer 2003:83).

2.2.5.2 The course of the disease

The whole HIV infection cycle begins with an acute phase that is called the acute primary infection stage or an acute sero-conversion illness (Onen 2002:297; Van Dyk 2005:40). Sero-conversion can be defined as the the point at which an HIV-negative "person's HIV status converts or changes from HIV-negative to HIV positive" (Van Dyk 2005:40). The sero-conversion phase usually occurs within six weeks after the initial infection of a person with HIV, and about 30-60% of all patients at this stage develop symptoms of an illness that is characterised by fever, headaches, fatigue, the swelling of lymph nodes, a rash and flu-like symptoms that last for only about a week or two (Onen 2002:297; Van Dyk 2005:40). During this sero-conversion stage, the viral load is very high indeed with each micro-litre of plasma containing more than ten million HIV particles. This is also stage at which the infected person is at their most infectious stage of the disease (Morris & Cilliers 2008:85; Van Dyk 2005:40).

But because of the emergency of cytotoxic T lymphocytes (CTL) and the neutralising antibody response, the viral levels in the human body in the subsequent stage actually decline until they reach a steady state at about 16-24 weeks. It is at this point after the initial infection that the infection slowly enters what is called *the latency phase* (AIDS Information Switzerland 2009:[1]; Morris & Cilliers 2008:85). After the latency phase, the increase in HIV virus particles and the rate at which new diseases and HIV-related

opportunistic infections appear begin to follow a well-known pattern and the diseases progresses steadily. The clinical progression of HIV infection can be described in terms of following four stages: (1) the initial infection stage during which they are no obvious symptoms, (2) the acute syndrome phase, (3) the asymptomatic (latent) period, and (4) the advanced disease period (Onen 2002:298).

The progression of HIV infection from the initial asymptomatic disease stage to the advanced illness stage known as AIDS, ranges in Africa are from between 34.2 months and 44.6 months (Onen 2002:298). Another study by Jaffar, Grant, Whitworth, Smith and Whittle (2004:463) calculated a median survival time for HIV-1-infected patients at 9.8 years. But other studies have reported wide variations in the amount of time that elapses between the HIV primary infection stage and the terminal AIDS stage and have produced cases that range from between one year to 20 years with an average interval of 12 years (AIDS Information Switzerland 2009:[1]; Zijenah & Katzenstein 2002:35). But all HIV-infected people will sooner or later begin to present with the full-blown AIDS syndrome unless the progress of the disease is somehow checked by means of, for example, the use of antiretroviral drugs (AIDS Information Switzerland 2009:[1]; Van Sighem, Danner, Ghani, Gras, Anderson & De Wolf 2005:212).

The definition of AIDS as a disease condition is fraught with inherent limitations if one relies largely on the clinical criteria that have been drawn up by the WHO (Onen 2002:300). To ensure consistency between the adult and paediatric classification of HIV/AIDS, the WHO later endorsed a new definition of HIV infection and AIDS in terms of which any diagnosis of HIV-related disease should rather be made in terms of clinical symptoms and signs (WHO 2006b:13). The 2006 classification (WHO 2006b:13) divides HIV disease into the following four distinct clinical stages: the asymptomatic stage (stage 1); the mild stage (stage 2); the advanced stage (stage 3); the severe disease stage (stage 4).

2.2.6 Signs and symptoms of human immunodeficiency virus disease

Each clinical stage of the progression of HIV disease is characterised by a set of symptoms and signs that determine the degree of severity that the patient is suffering. In addition to this, the signs and symptoms suggest ways and means of managing each particular stage of HIV disease. Table 2.1 sets out the stages of the HIV disease in

terms of their characteristic symptoms and signs (WHO 2007:16). Each of these clinical stages is characterised by a definite set of clinical conditions and clinical presentations. Although a patient may present with any of the conditions listed below, the HIV status of a patient (whether HIV positive or negative) must be confirmed because the disease staging and management needs to be supported by a positive HIV diagnosis (WHO 2004a:13).

Table 2.1: Clinical staging of HIV/AIDS for adults and adolescents

<p>Clinical stage 1 Asymptomatic disease, persistent generalized lymphadenopathy</p>
<p>Clinical stage 2 Moderate unexplained weight loss (<10% of presumed or measured body weight), recurrent respiratory tract infections, Herpes zoster, angular cheilitis, recurrent oral ulceration, papular pruritic eruptions, seborrhoeic dermatitis, fungal nail infections</p>
<p>Clinical stage 3 Unexplained severe weight loss (>10% of presumed or measured body weight), unexplained chronic diarrhoea that lasts for longer than one month, an unexplained persistent fever (above 37.6°C) that is either intermittent or constant for longer than one month), persistent oral candidiasis, oral hairy leukoplakia, pulmonary tuberculosis (current), severe bacterial infections (such as pneumonia, empyema, pyomyositis, bone or joint infection, meningitis or bacteraemia), acute necrotizing ulcerative stomatitis, gingivitis or periodontitis, unexplained anaemia (<8 g/dl), neutropaenia (<0.5 × 10⁹ per litre) or chronic thrombocytopaenia (<50 × 10⁹ per litre)</p>
<p>Clinical stage 4 HIV-wasting syndrome, pneumocystis pneumonia, recurrent severe bacterial pneumonia, chronic herpes simplex infection (orolabial, genital or anorectal, of more than one month's duration or visceral at any site), oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs), extrapulmonary tuberculosis, disseminated non-</p>

tuberculous mycobacterial infection,
Kaposi's sarcoma, cytomegalovirus infection (retinitis or infection of other organs),
central nervous system toxoplasmosis, HIV encephalopathy, extrapulmonary cryptococcosis including meningitis, progressive multifocal leukoencephalopathy, chronic cryptosporidiosis (with diarrhoea), chronic isosporiasis, disseminated mycosis (coccidiomycosis or histoplasmosis), recurrent non-typhoidal salmonella bacteraemia, lymphoma (cerebral or B-cell non-Hodgkin) or other solid HIV-associated tumours,
invasive cervical carcinoma, atypical disseminated leishmaniasis, symptomatic HIV-associated nephropathy or symptomatic HIV-associated, cardiomyopathy

(Source: Onen 2002:303; WHO 2007:16)

Table 2.1 (above) shows that the stages of HIV/AIDS, according to the WHO classification of 2006, can be divided into the following four stages. **Clinical stage 1** is characterised by acute infection but a symptom-free (asymptomatic) presentation – a stage that can last up to 12 years (AIDS Information Switzerland 2009:[1]). Even though the virus is replicating in the human body during this stage, the infected person shows no outward symptoms or signs of the disease.

During the so-called *latent stage* of the disease, infected people (unless they were tested for HIV) would not be aware that they infected with HIV and could therefore unknowingly and unwittingly infect their sexual partners. Despite the lack of symptoms and physical manifestations of the disease during stage one of the disease, the HIV is active in damaging and continuously undermining the integrity of the body's immune system. During this asymptomatic stage or phase, the CD4 cell count decreases by 40-80 cells/mm³ per year (Van Dyk 2005:41).

During **clinical stages 2 and 3**, a set of symptoms and signs that are caused by the advanced weakness and deterioration of the immune system, begin to manifest themselves. These symptoms include persistent fevers, nocturnal sweating, loss of weight, intermittent bouts of diarrhoea and a general deterioration in the patient's health status. The patient may also begin to experience frequent fungal infections of the mouth and oesophagus that are caused by candida or by viral illnesses such as shingles (Herpes Zoster) (AIDS Information Switzerland 2009:[5].)

During **clinical stage 4**, the immune system has more or less completely collapsed and the patient begins to present with the well-known symptoms and signs of AIDS. During this stage, a wide variety of infectious diseases and forms of cancer may appear. The patient will experience fungal diseases of the oesophagus, pulmonary inflammation, tuberculosis, viral diseases, parasitic diseases, rare tumours, as well as neurological diseases and a drastic loss of weight (the “wasting syndrome”). It is during clinical stage 4 (the AIDS stage) that the risk of patient mortality is highest.

Because immunosuppression can also be caused by a number of conditions including various kinds of cancers and other infections, this HIV/AIDS staging is positively confirmed after HIV antibody testing from a sample of the patient's blood (WHO 2004a:13).

2.2.7 Human immunodeficiency virus infection and testing

HIV counseling can be defined as a confidential dialogue that takes place between a client (patient) and a care provider. The purpose of counselling is to enable the client (the patient) to cope with anxiety and stress that is generated by their awareness of their potential HIV status (whether positive or negative), and to enable them to make important personal decisions on the basis of a confirmation of their HIV status (Ministry of Health, Government of Uganda 2003b:2.) Although HIV is a chronic disease, in many settings it is a terminal disease that requires proper pre-test counselling before an HIV test is undertaken and before the results are communicated to a patient. The most common approach to HIV counselling and testing throughout the world is called voluntary counselling and testing (VCT). In the sessions that are based on this model, the physician or health care provider informs the patient (in terms that they can understand) of all the salient facts that relate to HIV disease, and the meaning and implications of an HIV-positive or HIV-negative result.

This widely used approach is described as *voluntary* because a patient *voluntarily* agrees to undertake the test and receive the results. Voluntary counselling and testing is an indispensable foundation for both prevention and treatment (Abdool Karim & Abdool Karim 2003:1499). Other counselling and testing approaches include HIV Counselling and Testing (HCT) and Provider-Initiated Counselling and Testing (PICT). These alternative methods of counselling have been implemented by researchers and

health care providers in various settings in which they are more appropriate to the conditions that prevail in such settings. These alternative approaches will not be described in this study because they were not used in the setting in which the research took place.

The CDC recommends that patients must receive information about HIV testing, HIV infection and the possible outcomes and meaning of test results (CDC 2007:[1]). Since HIV screening is voluntary, it should always be performed in a setting of optimum confidentiality (Marum, Campbell, Msowoya, Barnaba & Dillon 2002:527).

The information that is given to patients includes an explanation of what HIV infection and disease are, and the possible meanings and implications of either a positive or negative test result (CDC 2006:[10]). The patient should then be offered an ample opportunity to ask questions, explain concerns and to accept or decline testing (CDC 2006:[10]). VCT is divided into pre- (“before”) and post- (“after”) test counselling, and it includes the provision of information, counseling about various methods of prevention and the services that are locally available to HIV-positive patients (CDC 2007:[1]). The information that is imparted also includes facts about the HIV test itself, its benefits and its possible consequences. After pre-test counselling has taken place and the client has freely given his or her consent to be tested, an HIV test is performed. VCT is critically important because it encourages people who may be HIV positive to be tested so that they can be aware of their HIV status and access the care and support that they require at the earliest possible stage of the disease (Marum et al. 2002:527). VCT is also important for those who are HIV-negative so that they can take whatever steps necessary to ensure that they will maintain their HIV-negative status in the future.

2.2.7.1 Negative test results

When a test result is negative, the health care provider will inform the client that unless he or she has engaged or participated in any act or event during the previous three months in which he/she might have been exposed to HIV infection, they can regard themselves as being uninfected by HIV (CDC 2007:[1]). But retesting is strongly recommended for the clients with history of possible exposure to HIV because at least six weeks to three months elapse before HIV antibodies can be detected by the most

common antibody tests (AIDS Information Switzerland 2009:[4]; CDC 2007:[2]; Puren 2008:97).

2.2.7.2 Positive (reactive) test results

For all clients who test positive for HIV, an additional confirmatory test is required. If the second test confirms that the client is indeed HIV-positive, they are informed of the meaning of the positive results in simple terms (CDC 2007:[2]; Puren 2008:97). A positive HIV test result means, of course, that the patient is infected with HIV, and that the client's body will become progressively weaker and more susceptible to opportunistic infections if the client's infection is not properly managed by the health care provider in terms of the best available treatments and precautions.

The results of a positive HIV test are personally communicated to the client in a post-test counselling session in order to ensure that the patient has a clear understanding of the implications of disease and of the available methods for managing the disease.

Careful and well-informed counselling and testing are a critical success factor in the delivery of ART because they constitute a point at which the client enters the treatment and management phase of the disease. They also help the health care provider to understand the extent to which the patient understands the possible implications of the disease and the services that are available to minimise its associated risks of progressive illness and death.

2.2.8 Tests that are used for the detection and management of infection

In order to determine whether or not an individual is actually infected with HIV, it is essential for an individual to be tested for HIV. One of the subsidiary purposes of testing for HIV is to screen apparently healthy individuals who wish to donate blood so that their blood products can be screened for HIV before they are used for transfusion into patients (Puren 2008:89-91). And HIV testing is also carried out (as has already been stated above) in order to confirm a diagnosis of HIV disease after certain clinical symptoms that are typical of HIV infection have already appeared in the patient. Thirdly, HIV testing is also performed in order to determine the degree of severity that the disease has reached prior to testing (Puren 2008:89-91).

HIV infection can be established by the identification of certain markers and can also be indirectly but accurately determined by the measurement of a number of antibodies generated by the presence of HIV in the human body. The presence of HIV infection can also be directly established by observing the presence of viral particles and circulating antigens or viral nucleic acids (Gueye-Ndiaye 2002:121). The positive presence of HIV infection can thus be determined in a number of different ways.

2.2.8.1 Detection of human immunodeficiency virus antibodies

Once an individual has been infected by HIV, the immune system of that person's body begins to develop antibodies to counteract the activities of the virus. Since these antibodies are produced by the body in an attempt to destroy the virus, they can be detected by certain laboratory tests, the results of which provide an indication of whether or not a person is infected with HIV (AIDS Information Switzerland 2009:[4]; Puren 2008:94-95). But in most clinical settings, HIV testing is currently accomplished by making use of rapid HIV tests. While HIV antibodies can be detected from between two and six weeks after infection, they can only be detected in most patients within a period of three months (AIDS Information Switzerland 2009:[4]). Serologic antibody testing is the testing method that is most widely used, and it consists of a screening test and a subsequent supplementary or confirmatory test (Gueye-Ndiaye 2002:122). The Enzyme-Linked Immunosorbent Assay (ELISA) test is the best known immunological test for detecting HIV antibodies (Puren 2008:93).

The outcome of these tests indicates whether a patient is HIV-positive or HIV-negative, and thus confirms the positive or negative HIV status of the patient.

2.2.8.2 Detection of the human immunodeficiency virus

The second category of tests actually detect the presence of the *virus itself* rather than the antibodies that are produced by the human body's reaction to the presence of the virus in the body. This test is designed to detect the HIV antigen that is one of the components of the virus's genetic material and is called the *polymerase chain reaction (PCR) test* (AIDS Information Switzerland 2009:[4]). The PCR test is used to measure the number of these virus particles in the blood (colloquially called "the viral load"). It has been reported that a two-fold reduction in plasma HIV RNA reduces the risk of

disease progression and progression to death by approximately 30% (Puren 2008:102). By extension, a four-fold and ten-fold reduction in the viral load would reduce the risk of progression of HIV disease progression by 55% and 65% respectively (Puren 2008:102).

The size of the viral load in the human body is therefore a factor of the greatest importance in the monitoring the treatment and management of an HIV infection (AIDS Information Switzerland 2009:[4]; Puren 2008:102).

2.2.8.3 Determination of human immunodeficiency disease severity

The health of an HIV-infected person depends on the condition of their immune system at any particular time (Van Dyk 2005:38). Since HIV/AIDS patients experience a variety of clinical conditions throughout the course of their infection, the severity and frequency of these conditions (which include opportunistic infections and malignancies) increase in proportion to a decline in the CD4 T-cell count (Mocroft, Barry, Sabin, Lepri, Kinloch, Drinkwater, Lipman, Youle, Johnson & Phillips 1999:1255). A third category of tests are therefore used to determine the severity of the HIV disease. These are tests that actually determine the CD4 count. Since the virus primarily attacks and destroys the CD4 cells, the ability to measure the number of CD4 cells in the blood is an accurate indicator of the status of any individual's immune system (Van Dyk 2005:38).

The measurement of the CD4 count is an important indicator of the health status of an HIV-infected person and is undertaken to determine the amount of damage that has already been inflicted on the patient's immune system. Once a patient 's treatment commences, the CD4 count is used in conjunction with the viral load test to measure the response of the body to treatment (Puren 2008:102). The "CD4 lymphocyte count at [the time of] AIDS diagnosis remains a strong predictor of [the patient's potential for] survival in the era of HAART" (Dore, Li, McDonald, Ree & Kaldo 2002:394).

2.3 TREATMENT OF THE HUMAN IMMUNODEFICIENCY VIRUS

A number of medications have been developed to disrupt or interfere with the action of HIV. These medications are called antiretrovirals (ARVs) (UNAIDS ca 2003:[1]). While they cannot actually completely *cure* “a person [who] has been infected with HIV, [they have the ability] (in a variety of their formulations) to act on different stages of the life-cycle of HIV” (UNAIDS ca 2003:[1]). HIV disease is thus currently managed by the administration of the combinations of appropriate antiretrovirals to infected patients. It is for this reason that the management of HIV disease is called “antiretroviral therapy” or “antiretroviral treatment” (ART). Since this form of managing treatment depends on administering a combination or regimen of antiretroviral medications over a period of time, this approach to treatment is also referred to as “highly active antiretroviral treatment” (HAART) (WHO 2006b:13). “The current goal of antiretroviral chemotherapy is to reduce viral load to the lowest level possible (undetectable) for as long as possible” (Amoroso et al. 2002:323).

The key objectives of managing HIV disease by means of antiretroviral treatments are as follows:

- Firstly, the treatment is designed to contain the unchecked expansion of the HIV virus in the body (this is called “virus suppression”). If the expansion of the virus is suppressed or prevented, the progression of HIV disease can be halted and the consequence is that the health status of the patient will improve (Van Sighem et al. 2005:212; WHO 2006b:13).
- Secondly, treatments are designed to manage and treat the presenting diseases and conditions that are typical of HIV infection and AIDS (WHO 2006b:13).

The key principles of HIV treatment are to:

- preserve and maintain the capacity of the immune function
- reduce the incidence of HIV-related morbidity and mortality
- encourage the maximum suppression of the viral load over a long period of time

- preserve the health status of the patient until more effective future treatment options become available
- minimise the impact and effects of toxicity
- reduce the possibility that the patient will transmit HIV to other people (Amoroso et al. 2002:323).

After the HIV status and clinical staging of the patient has been confirmed, ART is the principal treatment that is used to manage HIV disease. ART invariably effects improvements in the clinical status of an HIV-infected patient and effectively reverses the progress of the clinical stages in patients who present with symptomatic diseases and conditions (WHO 2006b:13).

2.3.1 Antiretroviral therapy for the human immunodeficiency virus

The HIV has three critical enzymes that it requires for its replication and propagation. These enzymes include reverse transcriptase (p66/55), protease (p10) and integrase (p32) (see figures 2.1 and 2.2 for stages 4, 10 and 5 respectively). The commonest antiretroviral medicines that are used in the treatment of HIV include nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTI), and protease inhibitors (PI) (Wood 2008:504). The reverse transcriptase inhibitors (including NRTI and NNRTI drugs) indirectly prevent the HIV viral genome from being incorporated into a human host cell by blocking the enzyme reverse transcriptase that is used by the virus for viral DNA synthesis. The protease inhibitors block the enzyme protease that is responsible for the formation of new viruses (AIDS Information Switzerland 2009:[5]; Wood 2008:509).

2.3.1.1 Antiretroviral medicines and regimens

The NRTI drugs and their accompanying acronyms include zidovudine (AZT), stavudine (d4T), lamivudine (3TC), emtricitabine (FTC), tenofovir (TDF), abacavir (ABC) and didanosine (ddi). The NNRTIs include efavirenz (EFV) and nevirapine (NVP) (Gilks,Crowley, Ekpini, Gove, Perriens, Souteyrand, Sutherland, Vitoria, Guerma & DeCock 2006:506.) To optimise the success of any HIV treatment regimen, these HIV ARVs are used in combinations that are referred to as “HAART” (Wood 2008:505). HAART is therefore the name that is being given to the treatment regimens that are

recommended by the world's leading HIV experts because they function aggressively to suppress viral replication and the progress of HIV disease (Amoroso et al. 2002:323). HAART consists of “two nucleoside reverse transcriptase inhibitors (NRTIs) and [one] non-nucleoside reverse transcriptase inhibitor (NNRTIs) or a protease inhibitor (PI)” (Amoroso et al. 2002:323; WHO 2006b:18-19). HAART suppresses the level of the virus in the blood and lymph nodes and thus slows down the progression of the disease (AIDS Information Switzerland 2009:[5]; Van Sighem et al. 2005:212).

2.3.1.2 *Regimens used in the treatment of the infection*

The combination of three or more ARV medicines are referred to as “regimens” (WHO 2006b:18-19). For all patients who are commencing treatment (i.e. patients who have never been treated with antiretroviral medicines before), the recommendation is that their treatment should begin with a first-line regimen. It is only after a first-line regimen has been observed to fail or be ineffectual (because the virus does not respond to the treatment) that a second-line regimen (and other regimens thereafter) are recommended (WHO 2004a:11; WHO 2006b:18-19.) The WHO public health approach to ART recommends that patient management should focus on the “four Ss of simplified clinical decision making: when to start, when to substitute for toxicity, when to switch treatment after failure, and when to stop” (Gilks et al. 2006:506).

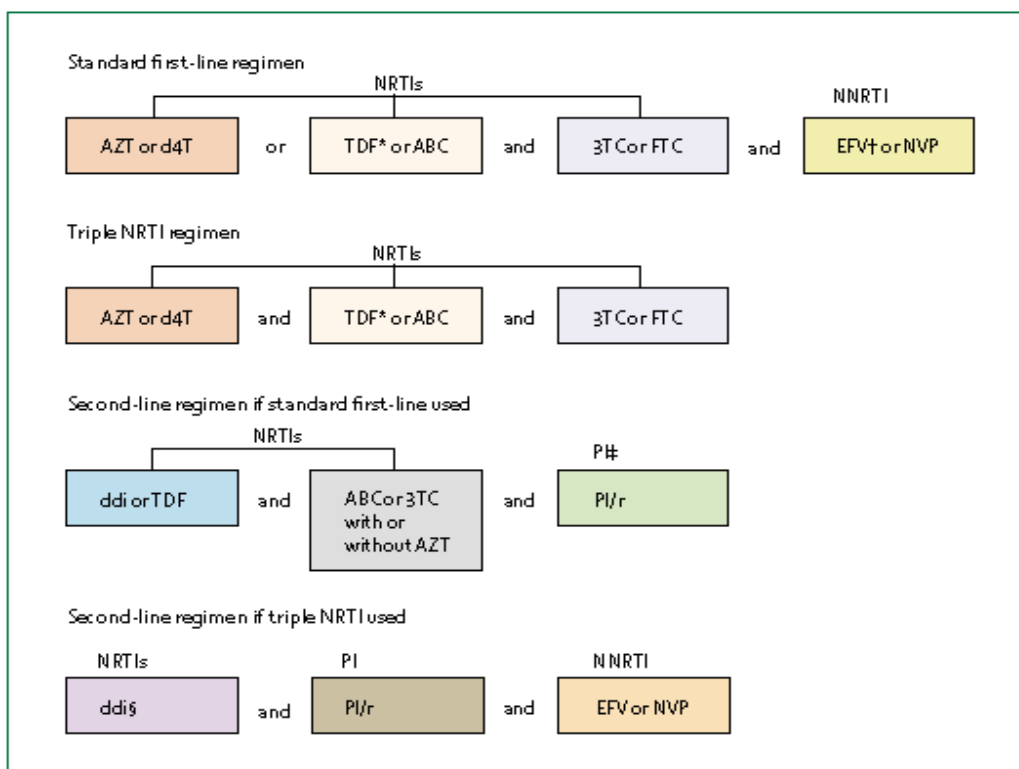


Figure 2.3: Recommended antiretroviral treatment regimens for HIV management

(Gilks et al. 2006:506)

Figure 2.3 (above) indicates that the recommended first line regimens include: [AZT + 3TC + EFV] or [AZT + 3TC + NVP] or [D4T + 3TC + EFV] or [D4T + 3TC + NVP] or [TDF + 3TC + NVP] and the other combinations listed above. The recommended second-line regimens include: [ddi + 3TC + PI] or [TDF + 3TC + PI] or [ddi + PI + EFV] (Gilks et al. 2006: 506; WHO 2004a:16).

2.3.1.3 Guidelines for starting antiretroviral treatment

Since there is no cure for HIV disease, HIV infection is a lifetime condition that can only be contained by means of ARVs. In the early nineties, antiviral therapy was used only for the treatment of advanced cases of HIV infection. ART is currently recommended for all stage three and stage four manifestations of HIV disease (AIDS Information Switzerland 2009:[5]). When the health-care provider initiates treatment in stage three of the disease, he or she does it in the hope of “firstly, stopping further proliferation of the HIV virus and destruction of the immune system, thus halting the progress of the disease; secondly, of suppressing the formation of resistant HIV variants; and, thirdly, of reducing proneness to infection” (AIDS Information Switzerland 2009:[5]). The

commencement of an ART regimen should therefore result in an improvement in the clinical health status of the patient and bring about an effective reversal of the clinical stage in patients with symptomatic diseases or conditions (WHO 2006b:13). In Uganda, ART is recommended for “WHO stage IV disease – irrespective of [the] CD4 count or advanced WHO stage III disease, for any patient at any stage of HIV disease [with] a CD4 count of 200 cells/ μ l (and below) or any patient with tuberculosis and a CD4 cell count of between 200 and 350/ μ l” (Ministry of Health, Government of Uganda 2003b:11).

These guidelines were applicable in the early 2000s and were designed for patients whose somatic immunity had already been severely compromised. In some patients, the damage to their overall health status may already be so extensive before the commencement of treatment, that the treatment itself may be relatively ineffectual. This study analyses and discusses the key indicators of when access to ART will be most effective. Indicators of the severity of the patient’s illness on presentation at the hospital included the average length of the patient’s stay in the hospital before death intervened, the median length of hospital admission, and out-of-pocket payments. This study analyses and discusses the mortality trends of a number of HIV-related and non-HIV related conditions.

2.3.1.4 *Antiretroviral treatment failures*

Treatment failure in this context can be defined as the clinical and CD4-related manifestation of treatment failure. It is realistic to assume that clinical treatment may be failing when new opportunistic infections or malignancies that signify the progression of clinical disease or the recurrence of previously treated opportunistic infection appear in the patient. Treatment failure can also be suspected if there is an onset or recurrence of WHO Stage III conditions (such as, for example, HIV wasting, chronic diarrhoea, and prolonged fevers of unknown aetiology, recurrent invasive bacterial infections, or persistently recurrent mucosal candidiasis). The failure of a CD4-related treatment is almost certain when the CD4 cell count returns to its to pre-therapy baseline (or when it sinks below that level) in the absence of any other concomitant infections that might account for a transient CD4 cell decrease or a >50% reduction in the CD4 cell count in the absence of any other concomitant infection that would explain a transient CD4 cell decrease (WHO 2004a:23).

It is worth noting that HIV is unlike any other chronic disease known to human beings because “effective control of HIV using vaccines and drug therapy...is compromised by the massive evolutionary potential of this virus” (Williamson & Martin 2008:109). This potential for evolution in the virus itself combined with the “error-prone nature of the HIV” reverse transcriptase enzyme, ensures that multiple mutations of the virus can occur quite rapidly (Wood 2008:521). In those cases where such changes in the structure of the virus are a result of treatment failure, they are greatly enhanced when HIV is exposed to a low-potency drug regimen or inadequate drug levels (as is the case when patients fail to participate in an optimal ART adherence regimen) (Wood 2008:520).

2.4 FACTORS THAT FUEL THE SPREAD OF HIV IN AFRICA

As earlier highlighted, The greatest burden of HIV/AIDS globally is concentrated in sub-Saharan Africa (UNAIDS & WHO 2007:7). “Infection rates in adults in South Africa, Botswana, Zimbabwe, and western Kenya range from 20% to 40%, which is higher than anywhere else in the world” (Halperin & Epstein 2004:4). The most obvious question that is raised by this extraordinary phenomenon is: *“What accounts for this high prevalence and burden of disease in sub-Saharan Africa?”*

The association between the absence of male circumcision among many males in this region and the high prevalence HIV partly explains the four- to five-fold difference in the HIV rates between southern and Western Africa (Halperin & Epstein 2004:4; Quinn, Wawer, Sewankambo, Serwadda, Li, Wabwire-Mangeni, Meehan, Lutalo & Gray For the Rakai Project Study Group 2000:928). But there are also other factors that have fuelled the high incidence and prevalence of HIV infection and the consequent spread of HIV disease in sub-Saharan Africa that are clearly visible from a comparison of the statistics of HIV-related mortality and morbidity from this region and those that describe the incidence of HIV infection in other regions of the world. These additional factors are discussed below.

2.4.1 Factors influencing the spread of the virus

An increased susceptibility to HIV infection is associated with numerous environmental, cultural, socio-economic, behavioural and racial factors (Benatar et al. 2004:277). Studies have shown that African men do not have more sexual partners in number over a specified period than men in all the other regions of the world, and that a very small percentage of women report contact with five or more sexual partners a year. Studies have shown that the promotion of condoms as a prophylactic (barrier) against the disease and recommendations that men should use condoms during sexual intercourse have been the cornerstone of HIV prevention efforts in Africa for many years. But a recent review of the relevant factors states that “no clear examples have emerged yet of a country that has turned back a generalized epidemic primarily by means of condom promotion” (Halperin & Epstein 2004:5.)

It is now widely recognised that the factors that have fueled the HIV/AIDS epidemic in Africa (and especially in sub-Saharan Africa) are both multidimensional and complex (Benatar et al. 2004:277). Of notable interest in this regard is the observation that, in Africa, men and women have been reported to have more than one concurrent (ongoing) sexual partnerships that overlap for many months or years (Halperin & Epstein 2004:4). “This pattern of sexual behaviour differs from that of the serial monogamy more common in the west, or the one-off casual and commercial sexual encounters that occur everywhere else [in the world]” (Halperin & Epstein 2004:4). By making use of mathematical modelling, Morris, Serwadda, Kretzschmar, Sewankambo and Wawer (ca 1997:[1]) established the impact of concurrency on HIV transmission by comparing the spread of HIV in populations where serial monogamy was the norm and in settings where long-term concurrency was the norm (Halperin & Epstein 2004:5). It was noted that “although the total number of sexual relationships was similar in both populations, HIV transmission was much more rapid with long-term concurrency – and the resulting epidemic was ten times greater” (Halperin & Epstein 2004:5).

One is therefore lead to conclude that, in sub-Saharan Africa, unlike in Asia and Europe, it is the practice of concurrent sexual relationships that has fuelled the spread of HIV (Halperin & Epstein 2004:5). This concurrency of sexual partnerships accounts for the significant difference in HIV prevalence between sub-Saharan Africa and the rest of the world.

One may sum up these factors by saying that the high incidence of multiple concurrent sexual partners, the low rates of condom usage and the low male circumcision coverage in various parts of Africa, have significantly fuelled the spread of HIV in sub-Saharan Africa (Benatar et al. 2004:277).

2.4.2 Myths and misconceptions

Among the factors that are fuelling the spread of HIV in sub-Saharan Africa are the many myths and misconceptions that relate to HIV infection and disease. These myths and misconceptions have contributed significantly to the spread of the virus and have grossly undermined and nullified the utility of the interventions that are being used to halt or slow down the spread of HIV in sub-Saharan Africa. It is this an astonishing fact that during the quarter of a century in which this disease and its treatments had been better and better understood, none of the interventions that have been so successful in other regions of the world have resulted in a sustained reduction in the incidence of HIV/AIDS in sub-Saharan Africa (Shelton 2007:1809). It is because of this that these life-threatening myths and misconceptions need to be properly understood and debunked (not only by health care professionals but by the public at large) if the interventions that had been successful in other parts of the world can also make a profound difference to the HIV infection rate in sub-Saharan Africa.

There are a number of misconceptions that impede the successful prevention and treatment of HIV. One of these is that *HIV spreads like wildfire*. But this is simply untrue. On average, in typical cases, HIV does not spread like wildfire. Although an HIV-infected person may be very infectious in the first weeks after infection (Cassell & Surdo 2007:492; Shelton 1809), they are not as infectious in the subsequent latent phase of the disease. There is also a myth that it is sex workers who contribute significantly to the spread of HIV. This theory also does not hold water because, in sub-Saharan Africa, formal sex work as a profession is uncommon, and cannot therefore be a significant contributor to the prevalence of HIV in this region (Shelton 2007:1809).

Other myths encourage the belief that certain behavioural patterns on the part of *men* are responsible for the unusual prevalence of HIV in this region. But it is important to emphasise the fact that in a heterosexual epidemic (such as the AIDS epidemic in sub-Saharan Africa), a significant number of *women* must also have multiple partners if this

factor is to be regarded as responsible for the rapid spread of a generalised epidemic in this part of the world (Cassell & Surdo 2007:492; Shelton 2007:1809).

There is also a widespread misconception that poverty and discrimination contribute significantly to the high prevalence of HIV-infected people in sub-Saharan Africa. Paradoxically, however, the prevalence of HIV has been shown to be much higher among the wealthier sectors of society than among poorer people, perhaps because there is a correlation between wealth and mobility and a high incidence of concurrent sexual partnerships (Shelton, Cassell & Adetunji 2005:1057-8; Shelton 1809). Many researchers have also regarded condoms as the most effective intervention for containing the HIV epidemic (Shelton:1809). But condoms (when used alone as an intervention) have been shown to have a limited effect on the reduction of HIV infection in the context of an epidemic (Shelton 1809). Since many people (mostly men) are strongly averse to using condoms (especially in the context of a regular and ongoing relationship), they tend to use them intermittently or not at all (Shelton 2006:1947; Shelton 2007:1809).

Another myth that has contributed to the spread of HIV/AIDS in Africa are those that are based on ignorance and a lack of recognition of the fact that the risk of HIV infection is equally likely for all sexually active individuals (Benatar et al. 2004:293). There are others in Africa that still blame the epidemic on the effects of witchcraft while others attribute AIDS to the anger of the spirits of ancestors who have not been adequately appeased and propitiated. There are also some black South Africans who believe that white people introduced HIV as a means of punishing blacks after the demise of apartheid in South Africa (McGeary 2001:[4] Benatar et al. 2004:277). But since the appearance and diffusion of the virus preceded the democratic revolution of 1994 in South Africa, this belief is yet another rationalisation of a disease whose dynamics are still imperfectly understood. Anecdotal evidence suggests that these myths and misconceptions are important factors that impede the effectiveness of HIV prevention programmes in rural clinics (Benatar et al. 2004:294). The most abhorrent of all these myths and misconceptions is the belief “that having sex with a virgin will cure HIV/AIDS” (Benatar et al. 2004:2794).

This brief description of the myths and misconceptions that surround the phenomenon of HIV/AIDS and the behavioural factors that are associated with the spread of

HIV/AIDS in the sub-continent, indicates why the HIV virus continues to spread so prolifically in sub-Saharan Africa. Despite the numerous efforts that have been made to mitigate the spread of the virus, a great number of new infections still occur on a daily basis in this region (UNAIDS 2008b:5). Shelton (2007:1811) points out that, in the context of these myths and misconceptions, “our priority must be on the key driver of generalised epidemics – concurrent partnerships”.

An examination of all available data indicates that the main factor that is contributing to the high prevalence and burden of HIV disease in sub-Saharan Africa is the fact that sexually active human beings engage in concurrent or overlapping sexual relationships.

2.5 THE IMPACT OF HUMAN IMMUNODEFICIENCY VIRUS DISEASE

HIV/AIDS has exerted a significant and destructive socio-economic impact on communities, on the resources of health systems, and on the overall development of all the countries of the subcontinent – especially those countries in which the incidence and prevalence of HIV infection are high.

“HIV/AIDS has brought about a global epidemic far more extensive than what was predicted even a decade ago. Still rapidly growing, the epidemic is reversing development gains, obliterating millions of lives, widening the gap between rich and poor, and undermining social and economic security. It has become a major cause of disease burden in South Africa, and arguably the single most [significant] phenomenon that will shape future demographic, health and development trends in the country” (Benatar et al. 2004:276).

2.5.1 Mortality trends in sub-Saharan Africa

As highlighted earlier, in 2008, an estimated 75% of all AIDS-related deaths throughout the world occurred in sub-Saharan Africa (Sani, Mohammed, Adamu, Yusuf, Samaila & Borodo 2006:862; UNAIDS 2008:5). In the 1990s, HIV-related mortality contributed to 40% - 69% of the overall mortality rate in high-prevalence settings (Lopman et al. 2006:189; Nunn et al. 1997:[4]). Another study indicates that the hospital mortality rate that was attributed to AIDS-related illnesses was 43% among females and 37% among males (Sani et al. 2006:864). In other studies carried out in rural settings in Tanzania,

65% and 60% of male and female deaths (respectively), and 74% of all deaths people aged between 35 and 44 years old, were attributed to HIV (Senkoro, Boerma, Klokke, Ng'weshemi, Muro, Gabone & Borgdorff 2000:194,198).

A study undertaken Ethiopia concluded that the mortality rate was five times higher in 2001 than the mortality rate in 1984 mortality. This demonstrates the severe impact of HIV on the causes of mortality among populations of the subcontinent (Sanders, Araya, Kebede, Schaap, Nagelkerke & Coutinho 2003:1212.) An HIV prevalence between 25 and 30% was detected in Lusaka, Zambia, and the likelihood of dying between the ages of 15 and 60 was very high because the death rate of 778 per 1 000 of the Zambian population was demonstrated as being due to the effects of HIV/AIDS (Kelly, Feldman, Ndubani, Baboo, Timaeus, Farthing & Wallman 1998:883).

2.5.1.1 Causes of death in sub-Saharan Africa

In Zambia, the most frequently reported causes of death had been reported as being due to diarrhoea (20%), tuberculosis (7%) and HIV/AIDS (3%) (Kelly et al. 1998:883).

In general, the adult mortality rates have risen substantially in East and Central Africa. In the absence of other factors, the high prevalence of HIV among local populations suggests that these excessive mortality trends are being driven by the patterns of HIV prevalence in the populations as a whole (McMichael et al. 2004:1156).

2.5.1.2 Mortality trends and the risk of death

In Abidjan, Ivory Coast, with an estimated HIV sero-prevalence of between 11% and 15% between 1985 and 1992, mortality doubled in the urban population (Garenne, Madison, Tarantola, Zanou, Aka & Dogoré 1996:1282). In Uganda and Zambia, the rates of premature mortality doubled or tripled, and the possibility of adult death doubled (McMichael et al. 2004:1156; Nunn 1997:[5]).

This kind of mortality trend is further exemplified in Zimbabwe, where the highest increase in mortality was noted among males aged between 15 and 55 years old. The probability of death has therefore “increased from 0.15 in the mid-1980s to 0.5 in the late 1990s” because of the ravages of HIV-related illnesses (McMichael et al. 2004:1156). In another study, the overall mortality rate among adults was fixed at 12.5 per 1000 people per year *with* HIV/AIDS in comparison to 7.0 per 1000 people per year *without* AIDS (Le Coeur, Halembokaka, Khlat, Brouard, Purhucence, M’Pele´, Baty, Barin & Lallemand 2005:1685).

In Uganda, fully one third of all adult deaths in 2005 were ascribed to HIV-related causes. HIV/AIDS therefore “continues to be the leading cause death” in this country (Hladika, Musinguzi, Kirungi, Opio, Stoverc, Kaharuza, Bunnella, Kafuko, & Mermin 2008:509). It has been projected that global HIV/AIDS deaths will rise from the figure of 2.8 million annually in 2002 to a pessimistic worst-case scenario of 6.5 million deaths per year in 2030 – even if one makes the assumption that ART access will reach an 80% coverage by the year 2012 (Mathers & Loncar 2006:8).

HIV/AIDS has therefore increased the overall mortality rates in all the populations of the world – especially for males, and has increased the risk or probability of death, especially in the countries of sub-Saharan Africa where most of these AIDS-related fatalities occur.

2.5.1.3 Demographic impact of the human immunodeficiency disease

In addition to the overall impact of HIV prevalence on mortality, Stanecki and Walker (2002:289) noted that all demographic indicators are affected by a high HIV prevalence. Demographically, 58% of all those living with HIV/AIDS are women, and about a third of all PLWHA are between the ages of 15 and 24 years old. In addition to this, women are affected at an earlier age when compared to men (Benatar et al. 2004:276, 283.)

Demographically, in settings with a high prevalence of HIV, women experience a higher rate of HIV infection than do males, and they are also affected at an earlier age than are men in all settings where there is a high prevalence of HIV-infected people.

2.5.2 The impact of human immunodeficiency disease on life expectancy

The average life expectancy of the population is reduced by between 15 and 20 years in countries where there is a high rate of HIV-infected people when one compares such countries to those with a low prevalence of HIV infection reported (Mathers, Sadana, Salomon, Murray & Lopez 2000:1687). Another study by Mathers et al. confirms these figures. It reports an average reduction of between five and ten years of life expectancy due to the HIV factor alone in sub-Saharan African countries (Mathers et al. 2000:1687; McMichael et al. 2004:1156). In addition to this, the average life expectancy of black South Africans is expected to drop by nine years by the year 2011 as a result of the increasing rates of HIV/AIDS that have been reported in that country. By 2011, AIDS-related deaths will account for half of all the causes of death in South Africa alone (Benatar et al. 2004:279).

The epidemic has also increased the burden on the already drastically under-financed and resourced health services of the countries of sub-Saharan Africa, not only for the general population at large but also for the health care workers who have to cope with the burdens imposed by the increased rates of illness and death because of the HIV/AIDS epidemic (Benatar et al. 2004:298; Abdool Karim, Abdool Karim & Baxter 2005:43). Since the prevalence of HIV/AIDS has reduced the quantity and quality of health services available in developing countries in sub-Saharan Africa, the quality of public health services in these systems that are already dangerously overextended, has been undermined to the extent that the systems themselves have become a factor that contributes to the already-high mortality rates in developing countries in sub-Saharan Africa (Abdool Karim et al. 2005:43). In a study carried out in the Masaka district of Uganda, the average life expectancy was determined to be 42.5 years in 1997 (Nunn et al. 1997:[5]). HIV/AIDS has also contributed to similar reductions in the average life expectancy in all sub-Saharan African countries.

2.5.2.1 Age at the time of death in sub-Saharan Africa

In a study carried out in India, Teja, Sudha and Lakshmi (2007:558) have noted that the burden of HIV/AIDS mortality has shifted from the older generation to the younger generation. This trend in mortality rates is exactly the opposite of what epidemiologists expect in epidemics of this severity and magnitude. But it does mean that more and

more young people are dying prematurely in developing countries. In South Africa, the prevalence of HIV among adults rose from 12.9% in 1997 to 19.9% in 2004 – largely due to the increase in HIV infections among young women (Benatar et al. 2004:279).

In a study carried out in the Republic of the Congo, AIDS was determined to be the cause of death in 45.1% of patients fatalities, and “in the 25–44 years age group, AIDS was the cause of two-thirds of the deaths” (Le Coeur et al. 2005:1684). In the same setting in which this research took place; the effect of HIV/AIDS tripled the mortality rate among young adults (Le Coeur et al. 2005:1685). Significant increases in the mortality rates of young adults leads to a reduction in the mean and median age at death and a downward trend as more and more young people die at a younger and younger age and are exposed to higher risks of disease and death during their lifetimes. The unprecedented increase in the incidence of HIV/AIDS has shifted mortality trends more and more towards younger people – causing them to die prematurely and at younger ages.

These facts are indication of the impact of a high prevalence of HIV infections on mortality and life expectancy trends. In such settings, high rates of HIV infections have contributed to an increase in premature mortality, a reduced life expectancy and reductions in population growth. This brief review of the facts indicates that the high prevalence of HIV infections in sub-Saharan Africa is closely associated with high overall mortality rates in the population of all these countries. The introduction of ART into such settings has been reported (as was expected by health care administrators and epidemiologists) to increase the average life expectancy and median age of the population at the time of death. These changes in mortality trends are also closely associated with certain demographic changes.

2.5.3 Out-of-pocket payments and the average lengths of stay in hospitals

Since the government of Uganda has sponsored the availability of free ART to private-not-for-profit hospitals by means of dedicated (delegated) funds, one cannot use the amounts that patients pay to calculate the exact cost of the health services that are delivered to patients in such hospitals. The costs of service delivery can be partly calculated by taking user charges into account. Part of the cost that can be calculated from user charges must take into account the cost of the professional labour that have

to be paid out in salaries and allowances as well as the cost of utilities. The exclusion of these costs from the overall calculation of the cost of health services ensures that most members of the public should be able to afford the fees. Such a calculation also enables one to determine a break-even point that will ensure that these hospitals will continue to provide services to the public. These excluded costs are funded by means of delegated funds from the Ugandan government itself and from donor support funds. In this study, user charges were fees that were payable for theatre costs, pharmaceuticals and laboratory services.

Through an analysis of out-of-pocket payments, the researcher was able to determine the estimated direct cost of health services delivery to the patient in the hospital in which he conducted his research. (This calculation excluded the cost of food and the cost of ARVs, both of which are provided free to the all patients.)

By bearing in mind the fact that there are a variety of cost categories that a patient has to finance in a local setting during the process of accessing health care (and that such costs include what has to be paid for food, transport and communication), the researcher who undertook this study used user charges to estimate the direct cost of health service delivery for the patients who were admitted to the hospital. The focus of this calculation was the amount (user charge) represented the direct out-of-pocket cost of health services at the point of care to the patient. The researcher focused on the financial liability to the patient because the cost of health services is a key factor in determining the timely availability of and access to essential health services in a hospital of this kind. Late access to essential services (especially in cases of HIV infection), has been demonstrated to be strongly correlated with high rates of morbidity and mortality (Yisa, Akinola & Awolade 2004:53). When the direct cost of service cannot be afforded by an average member of the population, patients only consider accessing the hospital for treatment as the last resort. Patients will exhaust all other options for treatment and health care, including the use of traditional medicines from traditional healers, the services of private clinics and of herbalists before finally presenting themselves to the hospital (Yisa et al. 2004:53).

Therefore, in circumstances of above average cost of services, patients tend access health services late in the course of disease and at the time of accessing hospital services, the presenting condition is advanced and severe and with complications of the

disease. This study analysed the direct cost of services in relation to overall income of the population and variables that are indicative of late access to health services that may determine the possibility of death as an outcome of a hospital admission.

2.5.3.1 Average length of stay in the hospital

The average length of stay (ALOS) in a hospital can be defined and calculated as the total number of in-patient days (or “hospital days”) from the date of admission divided by total number of admissions or discharges (including the number of deaths) in a predetermined period (European Union Public Health Information System – EUPHIX 2009:[1]; Pennsylvania Department of Health 2001:[1]). The total number of in-patient days is represented by the sum of each daily in-patient hospital census for the time period under examination, while the total number of admissions can be represented by the total number of individuals who are admitted into the in-patient wards of the hospital during the period that is being considered. The ALOS is a vector that is used for monitoring trends and the efficiency of health care, and for the purposes of planning future forms of health care (Pennsylvania Department of Health 2001:[1]).

While the average length of a hospital stay (ALOS) is a key indicator of the degree of efficiency with which hospitals handle patients, it is also an indicator of the degree of severity of the conditions with which patients are presenting. ALOS is therefore determined by the age of the patient, the severity of the illness and the capacity of the hospital’s systems to manage the treatments and care that patients need, and by the efficiency with which hospitals discharge patients at the right time (Black & Pearson 2002:611). When one combines ALOS with the bed occupancy rate, ALOS is also a good indicator of the efficiency with which a hospital is able to deliver its services (Effe 2006:76). Hospital stays that are extended beyond the point at which patients can derive any further benefits, represent an unnecessary increase in the expenditure to which both the hospital and its patients incur. Black and Pearson (2002:611) have both observed how even the low percentage increase of 2.5% in ALOS expenditures ultimately result in “huge potential costs”.

In Northern Uganda, the average length of a hospital stay during the years 2004 and 2005 in four private-not-for-profit hospitals was 9.2 days (Effe 2006:76). In another study conducted in Northern Uganda, patients with AIDS-related illnesses stayed in the

hospital for an average time of 17 days and contributed 11.5% to the overall mortality rates recorded in the hospital (Fabiani, Accorsi, Aleni, Rizzardini, Nattabi, Gabrielli, Opira & Declich 2003:64-64). The impact of HIV-related illnesses on the length of time which patients remained in hospital should not therefore be underestimated.

In Britain, the average length of a hospital stay has been reduced from 11.7 days in 1980 to 6.95 days in 2002. This indicates an increase in the efficiency with which inpatients were managed during this period (Black & Pearson 2002:611). In other settings in developed countries, the average length of a hospital stay ranged from between 4.6 days (Staff 2009:[1]) and 10.0 (± 9.8) days (Cabre, Bolivar, Pera, Pallares & The Pneumonia Study Collaborative Group 2004:[2]).

In Northern Uganda, the prevalence of HIV among in-patients was 42%, and 37.2% of the available bed-days were taken up by HIV-positive patients (Fabiani et al. 2003:64-64).

The focus of this study in this population of hospital deaths was to determine the ALOS before death. This analysis is a key indicator of the trends in the severity of illness patients present with and a determinant of the capacity of the hospital to manage severe or critical illnesses that often result in death.

2.5.3.2 Out-of-pocket payments for hospital services

An *out-of-pocket payment* can also be defined as an expenditure in cash that is personally paid by the recipient in exchange for a service (Dictionary.com n.d.:[1]). The daily costs of maintaining patients in a hospital vary from country to country. In Uganda, out-of-pocket payments are an indicator of the direct cost of health service incurred by patients and/or their relatives. The researcher used an average out-of-pocket payment amount in this study to define the amount of money a patient or his/her relatives was required to pay for the services they received from the hospital (out-of-pocket payments are also referred to as “user charges” in Uganda).

Hospitals calculate user charges for the services rendered to patients on the basis of an established tariff, and expect patients or their relatives to pay out-of-pocket payments for services rendered. In the mission hospital setting in Kenya (similar to the hospital in

which the research undertook the present study), the hospital treatment costs per child were calculated at US\$ 88.2 for malaria, US\$ 142.2 for pneumonia, and US\$ 201.6 for meningitis (Ayieko, Akumu, Griffiths & English 2009:27). The literature indicates that there are wide variations in the average hospital costs per day among different kinds of hospitals in Africa. The ways in which hospital costs are calculated also vary, and depend on what is included and what is excluded from the cost calculation. In Mali, Mozambique and Algeria, for example, the cost per bed day in public facilities for a hospital with an 80% occupancy rate excluded drug costs but included food costs and ranged between US\$ 7.4 and US\$ 26.3 (Adam, Evans & Murray 2003:[8]). In South Africa, the cost of a day in hospital per patient (for services that included laboratory costs, length of hospital stay, therapy, blood products and imaging studies) was US\$ 225.7 for an average stay of 6.5 days for a patient who was being treated for firearm injuries (Allard & Burch 2005:592).

In Uganda and in the setting in which this study was performed, user charges are regarded as a method of recovering a certain amount of the costs from patients and as a payment for the use of health services and the administration of treatments. User charges are also regarded as a way of generating the shortfall in funds from the government and other funding agencies (Yisa 2004:49). In Uganda as well as in a number of other African settings, user charges in fact make a minor contribution to the actual operating costs of hospitals concerned (Yisa et al. 2004:50). In a study performed in Tanzania, it was calculated that patient fees for inpatient services only contributed 25% of the costs of service delivery (Flessa 1998:404).

The task of this study was to determine the ALOS and the out-of-pocket payments in the pre-free and post-free ART eras, and to find out whether there were any variations in the ALOS and out-of-pocket payments received from patients who had died from HIV/AIDS-related causes and those who died from non-HIV/AIDS-related causes. The researcher therefore investigated trends in user out-of-pocket payments for each recorded death in an effort to determine possible explanations for the impact of hospital deaths on user charges and in order to be able to compare similar factors in the pre-free and post-free ART eras.

2.5.4 The need to monitor morbidity and mortality trends

The impact of HIV/AIDS on mortality and morbidity trends makes it imperative to monitor vital mortality statistics.

“Reliable information on global and regional deaths by cause are an essential input to planning, managing and evaluating the performance of the health sector in developing countries. The numbers of deaths by cause influence the manner in which resources are allocated to different service programmes and research activities. An accurate assessment of current death rates by cause in different regions also forms the baseline against which new health programmes must be evaluated. Without a reasonable baseline, we shall not, in 5 or 10 years from now, be able to assess what has worked and what has failed. In addition, reliable information on deaths by cause is an essential input to the assessment of cost effectiveness of new technologies for disease control and health promotion” (Murray & Lopez 1994:447).

Few sub-Saharan Africa countries have implemented death-registration record systems in which up to 50% of the recorded information is complete. (The recording and coverage of vital statistics is about 50% in Kenya and Zimbabwe, and about 90% in South Africa.) This incomplete coverage of the vitally important statistics (including mortality data) implies that the health systems of sub-Saharan Africa do not possess accurate information about who is dying, when they are dying, and what they are dying from.

This lack of accurate information about mortality trends prevents researchers and health-care administrators from effectively monitoring the impact of interventions that had been targeted at reducing the burdens of disease and unwanted and unnecessary deaths.

2.6 HUMAN IMMUNODEFICIENCY VIRUS DISEASE IN UGANDA

“The HIV/AIDS epidemic in Uganda remains a serious public health challenge contributing a disproportionate burden of morbidity and mortality. The epidemic has had serious social and development impacts and has affected quality of life indices including child survival and life expectancy. It has also imposed a heavy burden on the health

care delivery system in the country in the last quarter of a century.” (Ministry of Health – Government of Uganda 2009:ii).

Uganda has been heavily hit by the effects of HIV/AIDS disease. The HIV/AIDS epidemic has significantly influenced morbidity and mortality trends and continues to be a critical factor in the delivery of health services in Uganda. The WHO estimated the adult (15-49) HIV prevalence in Uganda at between 3% and 7%, and at 7% in 2003 and 2005 respectively (WHO 2005b:1). Uganda is therefore considered to be a high prevalence setting with significant morbidity and mortality trends that are a direct result of the HIV/AIDS epidemic.

The impact of HIV/AIDS in terms of age, gender, race and ethnicity in Uganda has been largely summarised by the Uganda HIV/AIDS sero-prevalence behavioural survey that was undertaken in 2004/2005. HIV prevalence was higher among women than among men (8% and 5% respectively), and the prevalence of HIV infection for both women and men increased with age and peaked between the ages of 30 and 34 for women and between the ages of 35 and 44 for men. This represented 12% for women and 9% for men (Ministry of Health – Government of Uganda 2006:101). This higher prevalence of HIV infection among females correlates with the high mortality due to AIDS that has been observed among females in Uganda when their mortality rate is compared with that of men (Le Coeur et al. 2005:1685; Sanders et al. 2003:1212). On the other hand, in the age group of people between 40 and 59 years of age, HIV was found to be more prevalent among men (Ministry of Health Uganda 2006:101).

The prevalence of HIV infection in urban settings was 10% in comparison with an infection rate of 6% among rural residents (Ministry of Health – Government of Uganda 2006:102). Uganda has also experienced a gradual increase in the prevalence of HIV among both sexes with wealth quintile from 4% among those in the lowest quintile to 9% in the highest quintile (Ministry of Health Uganda 2006:104).

Available records also show that malaria has been a leading cause of death in sub-Saharan Africa for more than century. But in the period covered by the last two decades, HIV/AIDS has exceeded malaria as a leading cause of death in sub-Saharan Africa – and it is the cause of even more fatalities among Africans than the effects of war (Benatar et al. 2004:276).

Women are therefore affected much at a much younger age than men, and have an overall higher prevalence of HIV than males during their sexually reproductive age (i.e. between the ages of 15 and 49). It is therefore evident that HIV/AIDS has exerted a direct socio-economic impact on the quality of human life in Uganda, and that the categories of people who are affected correlate with age, gender, wealth and place of abode (whether urban or rural).

In a background of high HIV/AIDS prevalence, to determine whether there was a notable change in mortality patterns, this study analysed the mortality patterns by age and gender and compared the pre and post-free ART eras.

2.6.1 Adult mortality trends in Uganda

In a hospital sero-survey conducted in 1999, more than 52.6% of the patients in the medical wards of a hospital in northern Uganda hospitals were HIV-positive. Because of this, HIV disease was said to be crowding out places that would have been taken by other patients in all the departments of the hospital (Fabiani et al. 2003:63-4). It was also noted that the mortality rates were higher among HIV-positive patients than they were among HIV-negative patients. HIV accounted for 38.0% of hospital bed-days and the average length of hospital stay (Fabiani et al. 2003:63-4).

This pattern of morbidity and mortality in Uganda because of the high prevalence of HIV infections corresponds with other findings by the WHO (WHO 2004a:2). The WHO estimated in 2002 that HIV/AIDS was the cause of 25% of all mortality in all age groups. HIV had therefore become the number one cause of mortality in Uganda, followed by malaria and lower respiratory infections which contributed 11% each to the overall mortality rate (WHO 2004a:2). These three conditions (HIV, malaria and lower respiratory infections) are therefore the cause of 47% of mortalities during the period under consideration (WHO 2004a:2; WHO 2006a:2). By 2003, it was estimated that 78 000 (or between 54 000 and 120 000) deaths in Uganda had been caused by AIDS (UNAIDS, UNICEF & WHO 2004:2). HIV/AIDS was the leading contributor (together with lower respiratory infections) to the global burden of disease that currently affects the human race (McMichael et al. 2004:1155). In Nairobi, Kenya, the hospital bed occupancy increased from 69% to 81% between 1985 and 1990 largely due to HIV/AIDS-related illnesses (Colvin 2005:337).

HIV/AIDS has therefore been (and continues to be) a major cause of mortality in Uganda because it causes more than a quarter of all deaths that are recorded in all health facilities. The introduction of freely available ART is therefore expected significantly to reduce the morbidity and mortality trends that have been attributed to HIV/AIDS in Uganda. Determination of morbidity and mortality trends in a rural setting was therefore the key focus of this study and through the analysis of mortality and morbidity data, the researcher demonstrated an overall trend of morbidity and mortality. Using a simple and straight forward approach to analysing trends, the researcher determined three year projections that can enable ART programme managers and district authorities look into the future mortality patterns so that specific targeted interventions can be implemented to optimise the positive benefits of ART of reducing morbidity and mortality.

2.6.2 Uganda's response to the human immunodeficiency virus epidemic

In response to the impact of HIV/AIDS, Uganda has implemented a national plan to increase the affected population's access to treatment. In June 2004, the Minister of Health, Mr Jim Muhwezi, announced that all people living with HIV in Uganda would in due course be granted free access to ARVs (WHO 2004b:[1]). Charging fees for ART services inhibits HIV-prevention activities because they discourage testing, reduce the uptake of antiretroviral therapy and can negatively affect adherence to ART of patients who have already begun to participate in an ART programme regimen (WHO 2005a:[1]). Uganda has accordingly been careful to adopt the WHO recommendation that all access to ART should be free at the point of service delivery since this is one of the key interventions that enhances access to ART and optimal medication adherence behaviour (WHO 2005a:[1]).

The introduction of ART of the population at large has obviously raised expectations that HIV-infected individuals will now also live longer. Since ART was expected to reduce morbidity and mortality rates, it was also expected to reduce the overall mortality of the population and to ensure an opportunity for even HIV-infected patients to live healthy and productive lives (Mermin et al. 2008:752).

Uganda is one of the 15 United States President Emergency Plan's focus countries, which collectively represent approximately 50% of all HIV infections worldwide

(PEPFAR ca 2008:[1]). The response of Uganda to HIV/AIDS has been “a model for the rest of sub-Saharan Africa” (PEPFAR ca 2008:[1]). “Uganda’s strategy involves strong public commitment; mass mobilization and education efforts; political openness; an extraordinary range of community and faith-based partners; and the political vision that recognizes HIV/AIDS as a threat to development, as well as a health problem” (PEPFAR ca 2008:[2]).

Since HIV/AIDS was reported to have been the cause of 25% of the overall mortality rate of the population in 2002 (WHO 2004c:2), the introduction of free ART to Ugandans should exert a significant impact on mortality trends by reducing mortality rates by between 1% and 25% – thus significantly reducing all the causes of mortality. This study determined the reduction in overall mortality in a rural setting and made recommendations that can be considered by programme managers in designing long term ‘reduction in mortality’ focussed ART interventions.

2.6.3 Achievements attributable to Uganda’s response to the epidemic

Uganda has been described as a “*pioneer* among African governments in its response to the HIV/AIDS epidemic” (PEPFAR ca 2008:[1]). The programme goal of the Health Sector Strategic Plan of the Ministry of Health of Uganda is [are] to expand economic growth, to increase the rate of social development and to accelerate the rate at which poverty is being eradicated (Ministry of Health Uganda – Government of Uganda 2000:5). In order to achieve this goal, the main objective of the Ugandan government has been to “reduce morbidity and mortality from all the major causes of ill health” (Ministry of Health – Government of Uganda 2000:5) and to reduce the various disparities in access to health care in Uganda (Ministry of Health – Government of Uganda 2000:5). It has therefore become imperative to carefully monitor the mortality trends in the country as a whole and to produce well-documented evidence-based mortality information if the health delivery system in Uganda is to achieve the goal and objectives that had been set by the Health Sector Strategic Plan.

Free access to ART in Uganda has dramatically increased over a period of between four and six years – and is revealing a shorter and shorter doubling time. By the end of 2004, 35 000 PLWHA were accessing ART. By August 2005, 67 369 people were doing the same, and, by June 2007, 106 000 PLWHA were receiving ART. By September

2008, 145 500 PLWHA were receiving ART (Mermin et al. 2008:758; PEPFAR ca 2008:[1]; Uganda AIDS Commission – Government of Uganda 2008:26; WHO 2004c). This can only be described, by any standards, as a remarkable achievement in the delivery of ART and in the willingness of those members of the HIV-infected population to participate in these programmes.

Uganda has achieved a reputation as being “one of the most successful countries in the *fight* against HIV/AIDS” after having been one of the countries that has been most ravaged by the effects of HIV/AIDS (McMichael et al. 2004:1156). In a study undertaken in rural Uganda, the mortality rate among HIV-positive adults was reduced by 90% among adults with HIV (Mermin et al. 2008:757). Similarly, the overall effect of ART on the overall mortality rate in Uganda has been found to be similar to or better than that which has been observed in facility-based studies in Europe, Haiti and other countries in Africa (Mermin et al. 2008:757). This is an indication that the introduction of ART into rural Uganda has effected a noteworthy reduction in the overall population mortality rates in these areas of the country.

This study analysed and compared the mortality patterns with the perspective of increasing ART access and coverage in a rural setting to determine whether in this rural setting a positive impact of ART had been observed and if not possible reasons for the observed trends.

2.6.4 The effect of tuberculosis in the Mpigi District of Uganda

It has already been mentioned, the Mpigi district of Uganda was the area in which this study was undertaken. The prevalence of tuberculosis (TB) among the population of the Mpigi district is currently on the increase, with 1 300 cases being reported annually (Miti 2008:[1]). The district tuberculosis and leprosy supervisor has expressed the opinion that the rise in the infection rate has been caused by the presence of the HIV among a large number of the district population. This is evident from a co-infection rate of 70% and 74% between the TB and HIV infection rates respectively (Miti 2008:[1]). The Mpigi district is therefore afflicted by a high burden of HIV/AIDS and TB, and the prevalence of TB is even now currently on the increase. This was one of the key justifications and motivations for the researcher to locate this study in the Mpigi district of Uganda.

The most recent HIV infection trends are a source of tremendous concern, with approximately 130 000 Ugandans contracting HIV annually (The New Vision 2009:[1]). Dr Kihumuro Apuuli, the Director General of the Uganda AIDS Commission, has “urged the Government to reinvent new strategies to fight HIV/AIDS”. He has also written: “To defeat HIV/AIDS, we need to start a new social movement to fight it [HIV].” (The New Vision 2009:[1].)

This recent development has encouraged all HIV programme managers to re-think their strategies for monitoring HIV/AIDS. This study is the researcher’s contribution to the new perspective of HIV programming in low resource settings of focussing on the overall goal of reducing morbidity and mortality through evidence based targeted interventions and careful morbidity and mortality monitoring.

2.6.5 Enhancing access to antiretroviral treatment in Uganda

The Uganda Ministry of Health has suggested various strategies for reducing the impact of HIV disease. Uganda has made pragmatic and challenging responses to the HIV/AIDS epidemic. These responses have ensured an increased awareness of HIV/AIDS, an increase in advocacy for greater attention to be paid to PLWHA, a reduction in the incidence of stigma and discrimination, the development and implementation of policies to combat HIV infection (which include HIV counselling and testing, ART, the Orphans and Vulnerable Children Programme, and other policies) (Uganda AIDS Commission – Government of Uganda 2008:8). These policies have ensured the implementation of a properly integrated HIV/AIDS program arena.

While it is therefore imperative to note that Uganda has made notable strides in the fight against HIV/AIDS, a great deal still needs to be done before access to ART for PLWHA becomes universal in that country. By the end of 2006, Uganda reported that 39% (91 500) of adults and children with advanced HIV infections were receiving ART (Uganda AIDS Commission – Government of Uganda 2008:8). By September 2008, of the 322 819 PLWHA who needed ART, 47.6% (153 719) were already receiving ART (Ministry of Health – Government of Uganda 2009:43). But this implies that 52.4% of PLWHA in 2008 still had no access to ART.

New HIV infections are occurring at an alarming rate – with an estimated 110 694 new HIV infections and 61 306 AIDS-related deaths occurring in Uganda in 2008 (Ministry of Health – Government of Uganda 2009:43). But the Ugandan national response (strategy) to the AIDS epidemic for the period between 2007/08 and 2011/12 gives a strategic national direction to efforts to address the problem of HIV/AIDS (Uganda AIDS Commission – Government of Uganda 2008:16). The overall goal of their strategy is “to achieve universal access for HIV/AIDS prevention, care and treatment and social support by 2012” (Uganda AIDS Commission – Government of Uganda 2008:16). In order to achieve this objective, the strategy includes the objective of increasing access to ART through all health centres, of improving the effect of all the factors involved in health service delivery, and the development of a National Communication Strategy (Uganda AIDS Commission – Government of Uganda 2008:17).

Ever since the launch of free access to ART in 2003 in the Ugandan public sector, the World Bank, PEPFAR/United States Agency of International Development (USAID), the Global Fund against AIDS, the Global Fund against Tuberculosis and Malaria (GFATM) and the government of Uganda, have all contributed to ensuring free access to ARVs for affected Ugandans (Uganda AIDS Commission – Government of Uganda 2008:25).

In spite of the extensive coverage that now ranges between 47.6% and 53% (Uganda AIDS Commission – Government of Uganda 2008:26), there is still a very high number of new infections and a high AIDS-related mortality in the country. Uganda needs to radically revise and rethink its current strategy on how to contain or halt this epidemic.

2.7 THE EFFECT OF ANTIRETROVIRAL TREATMENT ON MORTALITY

This section describes the impact of ARVs on morbidity and mortality trends. ARVs and ART are the most effective known form of clinical intervention for reducing HIV-1 mortality. ARVs are becoming increasingly available in the developing countries where 90% of HIV-infected people live (Mermin et al. 2008:752; WHO 2002:1).

Figure 2.4 (below) indicates the global trend of the number of adult and child deaths that have been attributed to HIV/AIDS over the seventeen-year period between 1990 and 2007. What is noticeable (and most encouraging) is that these figures reveal a downward trend that began in 2006.

Estimated number of adult and child deaths due to AIDS globally,
1990–2007

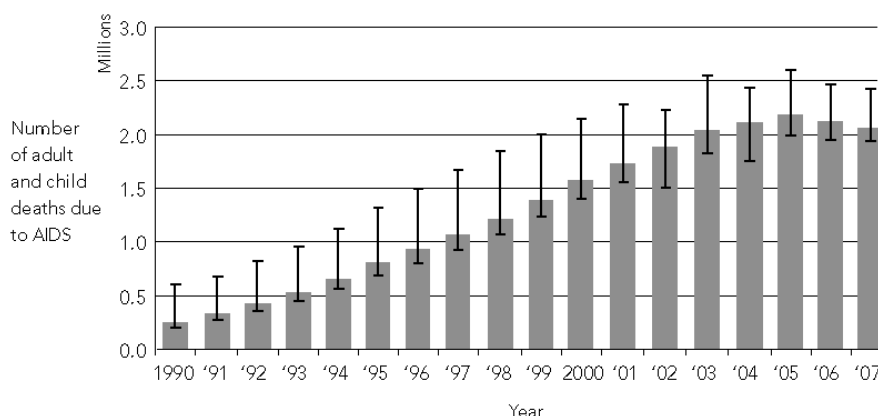


Figure 2.4: The estimated number of adult and child deaths due to AIDS throughout the world (1990-2007)

(Source: UNAIDS & WHO 2007:5)

Figure 2.4 (above) shows a progressive increase in HIV/AIDS-related mortality from between 1990 and 2005 and a slower but progressive downward trend thereafter from between 2005 and 2007. This encouraging news of this fairly recent downward trend in mortality rates from between 2.2 million deaths attributable to AIDS per annum in 2005 and the figure of 2 million deaths attributable to AIDS per annum in 2007, is largely a result of the increasing access that HIV-infected individuals have to ART (United Nations [UN] 2008:28). The burning question now is: “Are these changes in mortality rates also visible at the level of hospitals in the rural communities of Uganda?”

Experience of health care providers in India shows that patients who received antiretroviral therapy revealed better survival rates – even when they presented with advanced symptoms of the disease if one compares their mortality rates with those who were never on ART (Kumarasamy et al. 2003:83). Patients who commenced with an ART regimen when they had a CD4 <200 cells/ μ L demonstrated a 45-month average survival rate compared to those who were not on HAART – who demonstrated a 33-month survival rate (Kumarasamy et al. 2003:83). In another study, a 39% increase in ART utilisation caused death rates to fall from 7.0 (1996) to 1.3 deaths per 100 person years (2004), and AIDS-related deaths to decline from 3.8 (1996) to 0.3 deaths per 100 person years (2004) (Palella, Baker, Moorman, Chmiel, Wood, Brooks, Holmberg & HIV Outpatients Study Investigators 2006:29).

“The increasing availability of antiretroviral therapy through resources from governments, the Global Fund against AIDS, Tuberculosis and Malaria and other donor agencies is a major step forward in the global effort against AIDS” (Abdool Karim & Abdool Karim 2003:1499).

ART has therefore definitely made a significant impact on the increasing survival rate of PLWHA and in on the reduction of AIDS-related mortality rates and the overall death (mortality) rates throughout the world where free ART has been made available.

The survival rate of patients on ART was beyond the scope of this study. However, the researcher examined trends in median age at time of death to determine whether patients were dying at an older age in free ART era. The death at time of death was therefore a key indicator of adult survival patterns that will need to be further analysed by other approaches to determine whether the rural population in Uganda is actually living longer in the era of free access to ART and factors associated with increased survival.

2.7.1 Antiretroviral therapy and the risk of disease progression

The progression of HIV infection from its earlier stages of the most advanced stage of the disease (AIDS) is a key determinant of mortality. Increases in the incidence of the most advanced stage of HIV disease (AIDS) has thus greatly influenced morbidity and mortality trends. One of the objectives of initiating ART programmes is to slow down the average rate of progression that characterises HIV disease (Flanigan, Wools-Kaloustain, Harwell, Cu-Uvin, Kimaiyo & Cater 2007:1499). ARVs have in fact exerted a significant impact on the progression of AIDS, even among patients presenting with advanced symptoms (Van Sighem et al. 2005:212).

“HAART has been extremely successful in suppressing HIV infection, restoring immune function and improving health” (Flanigan et al. 2007:1499). HIV/ AIDS as a cause of disease has been reduced since the introduction of ART (Mocroft Ledergerber, Katlama, Kirk, Reiss, D'Arminio Monforte, Knysz, Dietrich, Phillips & Lundgren 2003:28; Carter 2008:[1]). This reduction in the prevalence of all AIDS-defining illnesses due to the systematic utilisation of ART has been associated with a dramatic “decline in the number of AIDS-related deaths” (Cohen, French, Benning Kovacs, Anastos, Young,

Minkoff & Hessel 2002:96). When one compares figures from the early-ART (1996-97) and the late-ART (1998-2002) eras, one immediately notices that the overall incidence of AIDS is 50% lower in the late-ART period (Mocroft et al. 2003:27).

In the Royal Free Hospital in London, the death rate among patients who are being treated with ART stands at one-sixth of pre-ART levels, while the incidence of new AIDS-defining illnesses and hospital admissions stand at one-seventh and one-fifth respectively of the rates that were prevalent in the pre-ART era (Mocroft et al. 1999:1258).

The cumulative effect of all the evidence assembled above leads one to the inevitable conclusion that increases in free access to ART has led to the reduction in the rate of progression of AIDS disease, and that this has significantly contributed to a reduction in the mortality rates due to HIV/AIDS. It is therefore of the greatest importance to monitor morbidity and mortality trends in all countries of the world where free access to ART has become available in order to determine the actual impact that is being made by free ART access. Since morbidity and mortality trends are used to guide decision-making and the adoption of the most effective interventions for minimising the risk of developing AIDS and its associated mortality rates, it is essential to implement accurate and comprehensive record-keeping in all the countries of the world and especially in the countries of sub-Saharan Africa.

2.7.2 The impact of antiretroviral treatment on morbidity and mortality

One of the key goals of ART “is to reduce HIV-related morbidity and mortality”, both at the level of patients and in the overall mortality rate of the population as a whole (Amoroso et al. 2002:323). It was therefore envisaged that the provision of free antiretroviral therapy would save lives and ameliorate the widespread suffering that is caused by HIV/AIDS (Abdool Karim & Abdool Karim 2003:1499). According to UNAIDS, “everywhere ART was introduced, spectacular improvements in the treatment of HIV patients ensured, dramatically reducing mortality among treated patients by about 70% and improving the quality of life” (WHO & UNAIDS 2002:3). In addition to this, “HAART has led to dramatic decreases in morbidity and mortality in those areas of the world where HIV infection is most prevalent” (Flanigan et al. 2007:1499).

In addition to reducing the rates of morbidity and mortality in those settings where ART has been introduced, the perceptions of the population at large with regard to HIV/AIDS has changed from “a death sentence to that of a manageable chronic illness” (WHO & UNAIDS 2002:3). As the use of ART in India, for example, has increased, and as death rates have declined from 25 deaths per 100 person-years in 1998 to 5 deaths per 100 person-years in 2003 (Kumarasamy, Solomon, Chaguturu, Cecelia, Vallsbhaneni, Flanigan & Mayer 2005:1526), the stigma that has widely been associated with HIV/AIDS is correspondingly diminished. Because of the increasing availability of resources for the procurement and distribution of ARVs, there has been a notable downward trend in the prevalence of HIV (Corbett, Marston, Churchyard & De Cock 2006:926).

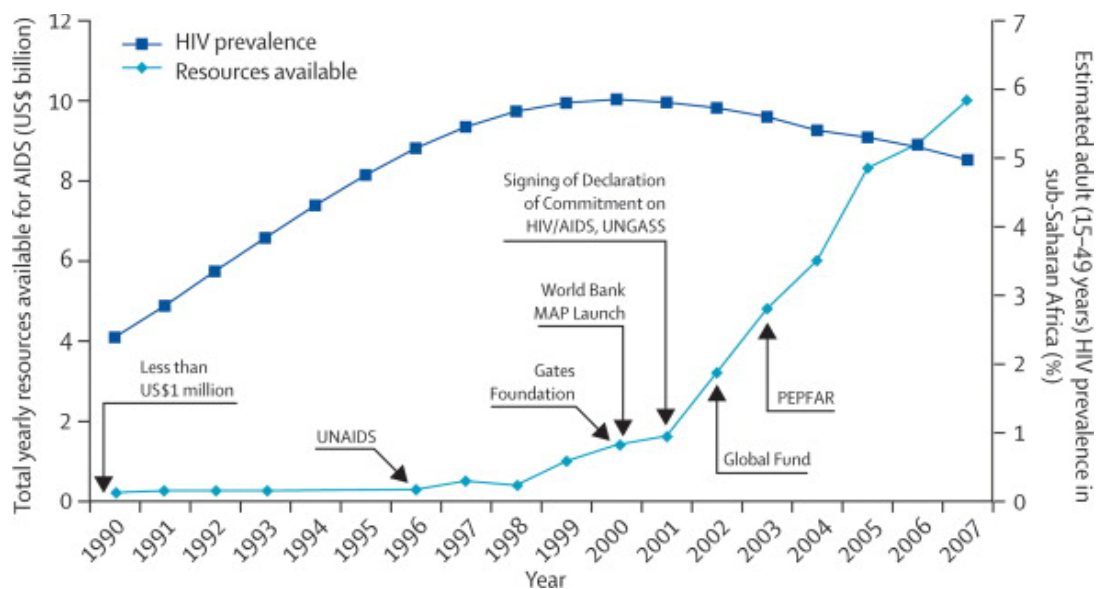


Figure 2.5: AIDS resources and prevalence between 1990 and 2007

(Source: Ellman & Simms 2008:1071)

Figure 2.5 shows that HIV prevalence among adults decreased in the years between 2001 and 2007 as increases in the funding and availability of resources to counteract the effects of the epidemic, have occurred. “Countries that have received tens or even hundreds of millions of dollars [during] the past few years (particularly those countries in East Africa) have recorded large reductions in adult prevalence rates” (Ellman & Simms 2008:1071).

The PEPFAR and the GFATM have significantly contributed to an increase in the number of people who are being treated. In high-prevalence settings, the increased availability of resources to fight the epidemics has been positively correlated with a reduction in HIV prevalence.

2.7.2.1 The impact of antiretroviral therapy on hospital admission trends

One of the key objectives of antiretroviral treatment has been to halt the multiplication of the HIV and thus reduce the risk of the progression of HIV disease among people who are living with HIV/AIDS (Van Sighem et al. 2005:212). Hospital admission trends have also shown that there is been a significant impact on the costs and workloads that have to be borne by public hospitals in particular. In northern Uganda, HIV positive patients have accounted for 37.2% of bed occupancy rates in medical wards (Fabiani et al. 2003:65). In a study carried out in England, the increased uptake of antiretroviral therapy among PLWHA has coincided with a decreased use of inpatient hospital services (Beck et al. 1999:2160). Similarly, in a private hospital in Chicago (United States of America), after the introduction of ART, HIV-related admissions fell by 50% between 1995 and 1998 (Kumar, Wester, Ariga, Singh, Smith & Pulvirenti 2000:[1]). There was also a 29% reduction rate in hospital admissions and inpatient deaths in HIV-positive patients between 1996 and 2000 following the introduction of free ART (Carter 2005:[1]; Smart 2008:[1]).

In 1996, each AIDS patient spent an average of 20 days in hospital per annum. But after the introduction of ART, the average amount of time that a patient spent in hospital fell to 11 days (Beck et al. 1999:2160.)

Despite the notable reductions in admissions caused by an increased access to and use of ART, there has been evidence of a rebound effect in hospital admission rates among people with HIV in the USA (Bauer, Mathews & Barber (2001:[1]). Admission rates in San Diego fell from 10 per 100 in 1993 to 3 per 100 person months in 1997. However, since that time, admission rates once again rose to 9 per 100 person months in 1999 (Bauer et al. 2001:[1]). In addition to this, while mortality rates among HIV-infected individuals since 1996 had fallen with the use of ART in developed nations, an increase in the number of deaths of HIV-infected hospitalised patients has been recorded (Teja et al. 2007:555).

The evidence cited above clearly shows that ART has made a far-reaching impact on the burdens that have been borne by hospitals, including a reduction in admission rates, in overall costs, in the amount of time that patients spend in hospitals and in mortality rates in general. These studies emphasise how extremely important it is to ensure that an effective monitoring of mortality trends in high HIV-prevalence settings will continue and be expanded in terms of both quality and comprehensiveness.

2.7.2.2 *The impact of antiretroviral therapy on causes of admission*

Ever since the introduction of ARVs, the reasons that had been recorded for patient admission have changed and that they are proportionately fewer in admissions for patients with the kind of opportunistic infections that are typical of HIV infection (Beck et al. 1999:2161). In another setting, there was a significant decline in the incidence of opportunistic infections and the risk of illness over time once free access to ART had become available (Carter 2005:[1]; Kumarasamy et al. 2005:1526; Mocroft et al. 2003:25-26;). In India, for example, the incidence of opportunistic infections was reduced to <2 cases per 100 person years after the introduction of ART, compared to up to 10 cases per 100 person years in patients who had not been on HAART (Kumarasamy et al. 2005:1526).

In spite of the documented reduction in opportunistic infections as a cause of admission and death in the ART era, Teja et al. (2007:559) have noted that 61% of deaths are still being caused by the opportunistic infections that are typical of HIV infection. Opportunistic infections have therefore remained the most common cause of death among hospitalized patients – even in the ART era (Teja et al. 2007:559).

But the evidence unambiguously suggests that ART has reduced the incidence of opportunistic infections. It is also evident that, despite the availability of free ART, HIV-related causes will continue to be important and will require careful monitoring. It is notable from the literature cited above that the impact of ART on opportunistic infections varies from hospital to hospital and should therefore be carefully monitored and meticulously recorded. This study focused on overall adults morbidity patterns by using hospital admission trends but did not delve into the analysis of the causes of admission but on the reported causes of death.

2.7.3 The impact of antiretroviral therapy on mortality trends

With an increased access to ART, the reasons for hospitalisation and causes of death for HIV-positive individuals are changing and must therefore be carefully monitored. This section explores the causes of mortality and the overall (“all cause”) mortality trends since the introduction of ARVs.

2.7.3.1 Impact of antiretroviral therapy on causes of mortality

In 2005, Carter (2005:[1]) reported a significant increase in liver disease and ART side effects as a cause of death among patients. In addition to this, there was an increase in the proportion of non-HIV-related causes of death, from 14% to 15% in the pre-ART era to 39% to 52% in the ART era (Teja et al. 2007:559; Bonnet, Morlat, Chêne, Mercié, Neau, Chossat, Decoin, Djossou, Beylot & Dabis 2002:197).

In a study that was undertaken over a 14-year period, the AIDS-related causes of death declined to 56% whereas the non-HIV-related causes of death *increased* to 32% (Crum, Riffenburgh, Wegner, Agan, Tasker, Spooner, Armstrong, Fraser and Wallace on behalf of The Triservice AIDS Clinical Consortium 2006:195) – with more deaths in the post-ART being caused by cardiac disease, trauma and liver disease (when one compares the incidence of these causes to those that prevailed in the pre-ART era) (Crum et al. 2006:198).

Another study has demonstrated that ART has improved the survival rate for patients who present with Kaposi's Sarcoma (KS) and Non-Hodgkin's Lymphoma (NHL), revealing an 81% and 84% reduction in the risk of death among patients with Kaposi's Sarcoma and Non-Hodgkin's Lymphoma patients respectively (Tam, Zhang, Jacobson, Margolick, Chmiel, Rinaldo & Detels 2002:918,919). Crum et al. (2006:195) have noted that opportunistic infections as a cause of death had been occurring less frequently and have declined from 59% in the pre-ART era to 24% during the ART era. It was also interesting and important to note that deaths in the post-ART era were less likely to be caused by an infection than in the pre-ART era (with 44% vs. 80%; P, 0.01) (Crum et al. 2006:196). The use of HAART has therefore improved the overall survival among PLWHA and it was a key area of interest for this study to determine the pattern of

causes of death in the pre and post-free ART eras and compare these patterns with other trends in sub-Saharan Africa and throughout the world.

2.7.3.2 The impact of ART on the overall mortality trends

Because mortality trends are closely related to morbidity trends, changes in morbidity trends affect mortality trends. The key objective of ART is to reduce the burden of both morbidity and mortality (Mermin et al. 2008:758). All programs need the kind of documentation that is able to show the exact extent of this impact.

Studies on responses to antiretroviral treatment in low-income countries, have indicated the degree of success in immune recovery and reductions in mortality (Carter 2005:[2]). Evidence shows that an increased access to ART in resource-limited settings with a high prevalence of HIV leads to an overall (“all cause”) reduction in mortality (Gomez, Romero, Bernal, Gonzalez-Outon, Briceno, Ruiz & Garcia-Gil 2004:[1]). In the United States of America, the overall mortality rate fell from 9% in 1996 to 6% in 2000 (Carter 2005:[2]). In another study in Malawi, the overall mortality decreased by 10% from 10 to 9 deaths for each 1 000 person-years of observation (Jahn et al. 2008:1607).

In KwaZulu, Natal, in the Republic of South Africa, there were declines in death rates from all causes of death between the first half of 2003 (before ART was introduced) and the second half of 2006 (Thaczuk & Differding 2008:[2]). The all-cause mortality rate in the 25 to 49 age group fell by 22%, and fell by 20% in men (Thaczuk & Differding 2008:[2]).

What is also of great interest is that the mortality rate after the introduction of ART varies by *gender*. Mortality was originally higher in men than in women (Braga, Cardoso & Segurado 2007:326; Nicastri, Angeletti, Palmisano, Samati, Chiesi, Geraci, Andreoni, Vella & The Italian Antiretroviral Treatment Group 2005:582). “The introduction of ARVs in 1996 significantly transformed the treatment of HIV and AIDS, improving the quality and greatly prolonging the lives of many infected people in places where the drugs are available” (UNAIDS ca 2003:[1]). Globally, the use of ART has improved therapeutic outcomes at the patient level and this has led to an overall reduction of morbidity and mortality rates among people living with HIV/AIDS (PLWHAs) (Kumarasamy et al. 2005:1528). Increased access to ARVs has also contributed to a 80% decline in HIV-

related deaths and an increased survival rate in India between 1997 and 2003 (Kumarasamy et al. 2005:1527). In yet another study, HIV-related deaths declined from 86% of all-cause deaths in the pre-ART era to 61% in the ART era (Teja et al. 2007:559). Similarly, deaths due to HIV/AIDS and tuberculosis fell from 22 and 23 per 1 000 person-years in women and men respectively in 2003/2004 (the pre-ART era), to 16 in women and 18 in men in 2005/2006 respectively (the era after the introduction of ART) (Thaczuk & Differding 2008:[2]). Another study found that women were significantly more likely to practice and achieve good adherence rates with 54% of females and 49% of males achieving more than 80% adherence (Nachega, Hislop, Dowdy, Lo, Omer, Regensberg, Chaisson & Maartens 2006:78). Women therefore reveal a better ART adherence than men in similar circumstances.

In Europe, between 1994 and 2001, HIV/AIDS-related death rates declined from 16 to 3 per 100 person-years of follow-up (Mocroft, Brettle, Kirk, Blaxhult, Parkin, Antunes, Francioli, D'Arminio Monforte, Fox, Lundgren & EuroSIDA¹ Study Group 2002:1666). Mortality due to AIDS therefore declined from 93% to 73% in a seven-year period (Mocroft et al. 2002:1666).

Similarly, in lower income countries such as Malawi, Uganda, Cote d'Ivoire and India, more than 75% of patients on HAART demonstrated excellent rates of viral suppression (Flanigan et al. 2007:1499). There has therefore been a significant decline in overall adult mortality rates within two years of ART programme roll-outs in a high-prevalence communities, even where ART coverage rates of only 11% have been reported (Thaczuk & Differding 2008:[2]). This shows that even with low ART coverage, ART has exerted a significant impact on mortality trends.

In Malawi, mortality due to AIDS has been reduced by 19% in the 15 to 60 year old age group within eight months of the introduction of free ART in a rural community clinic (Jahn et al. 2008:1607). It was interesting to note that because of free access to ART in the Malawi study, there was a 35% reduction in the mortality rate among a community of adults *who lived near the main road* (Jahn et al. 2008:1607). In another study carried out by Smith, Gardner, Phelps, Hamburger, Carpenter, Klein, Rompalo, Schuman and

¹ The EuroSIDA study is a prospective observational cohort study of patients followed in hospitals in European countries in addition to hospitals in Israel and Argentina (Copenhagen HIV Programme 2009).

Holmberg (2003:680), a 42% increase in ART usage decreased incidence of AIDS as a cause of death from 58% of all deaths in 1996 to 19% in 1999. In Ethiopia, over a five-year period of ART programmes administration, adult AIDS deaths were reduced by 50% (Reniers, Araya, Davey, Nagelkerke, Berhane, Coutinho, & Sanders 2009:511). "In populations with access to these drugs [ARV medicines], death rates have plummeted" (Rabkin, El-Sadr, Katzenstein, Mukherjee, Masur, Mugenyi, Munderi & Darbyshire 2002:1503). These are extremely encouraging statistics in the difficult battle to contain the damage inflicted by the HIV virus throughout the world.

In contrast to these encouraging reductions in mortality, not all ART programmes have been successful in reducing the rates of mortality that are attributable to HIV/AIDS. Smith et al. (2003:679) reported that the all-cause death rates among HIV-infected women remained unchanged between the pre-ART and ART eras.

In another study of mortality rates, there were actually increases during the first year in which ART was made available. Mortality rates also increased in low-resource settings in comparison to those in developed countries where mortality rates were reduced by the availability of ART (Braitstein, Brinkhof, Dabis, Schechter, Boulle, Miotti, Wood, Laurent, Sprinz, Seyler, Bangsberg, Balestre, Sterne, May & Egger 2006:821). Similarly, in contrast to the reported reductions in mortality rates with an increased access to ART, another study reported that while the virological response after the commencement of ART has improved over calendar years, such improvements have not translated into a corresponding decrease in mortality (May, Sterne, Costagliola, Sabin, Phillips, Justice, Dabis, Gill, Lundgren, Hogg, de Wolf, Fätkenheuer, Staszewski, d'Arminio Monforte & Egger 2006:451).

Another study revealed a notably higher death rate in the early HAART era compared to the later HAART era, and an 80% overall decrease in deaths from between 1990 and 2003 (Crum et al. 2006:195).

It is therefore clear that, in some settings at least, increased access to ART has significantly reduced mortality rates while, in other settings, mortality rates have not shown any significant change. It is also important to note that while some studies have reported a reduction in mortality rates over a short period of access to ART, other studies have reported that a reduction in mortality rates occur only after calendar years

and not after over a short period of time. In the present study, the researcher focused on a three-year period of access to ART and the three years before any free access to ART was available. He expected to find that specific mortality patterns would be observable during this period, and he devised three-year projections to enable health managers draw design effective interventions.

2.7.3.3 Survival trends and antiretroviral treatment

Studies have reported an overall reduction of between five and 20 years in life expectancy rates in sub-Saharan African countries because of the effects of HIV/AIDS (Benatar et al. 2004:279; Mathers et al. 2000:1687; McMichael et al. 2004:1156). In South Africa, it was projected that, by 2011, AIDS would be the cause of half of all the national deaths that will occur in the country (Benatar et al. 2004:279).

In India, the mean duration of survival from the date of HIV sero-diagnosis was 7.7 years (92 months) (Kumarasamy et al. 2003:83). In another study, the median time of survival after HIV sero-conversion before HAART was 8 years compared with 10 years during the early ART era and 12 years during the late ART era (Crum et al. 195). These statistics are, however, not conclusive because the onset of advanced HIV disease depends on a multitude of factors. The challenge in determining the time that elapses between infection and advanced disease arises out of fact that acute HIV infection is rarely diagnosed in African settings (Onen 2002:297). The experience from Southern India, in a low-resource setting similar to those found in sub-Saharan Africa, has reported that HIV patients on ART had been surviving for at least six months and the these patients displayed a median survival of three years (36 months) compared with patients who were not on ART and who displayed a median survival of 1.7 years (20 months) (Kumarasamy et al. 2005:1526). Crum et al. (2006:195) have also noted a decreasing trend in AIDS-related conditions as a cause of death from 80% in the pre-ART era, to 65% in the early post-ART era, and 56% in the late post-ART.

Although there is contradictory evidence about reductions in mortality after the introduction of ART to previous ART-free environments, there is mounting evidence that the introduction of ART into a high HIV-prevalence setting is associated with a reduction in the risk of the usual progression towards AIDS, and thus a corresponding reduction in the risk of mortality due to AIDS (Van Sighem et al. 2005:212). It is therefore worth

noting that “HAART has had a profound impact on the natural history of AIDS related opportunistic disease” (Dore et al. 2002:394). The advent of free ART has therefore basically transformed the whole complexion of the AIDS epidemic. But, because of this, changing trends in causes of mortality have to be very carefully monitored in view of increasing incidence of liver disease and the mortality rates that are attributable to the side effects of ARVs.

The median age at death is defined as “the age at which exactly half the deaths registered (or occurring) in a given time period were deaths of people above that age and half were deaths below that age” (Australian Institute of Health and Welfare (AIHW) – Australian Government: ca 2005[257]). The median age at death is significantly influenced by the age structure of a population as a whole (AIHW - Australian Government: ca 2005[257]). The median age at death changes over time if the age structure or distribution of the population changes or because of changes in mortality patterns that influence mortality rates in specific age groups when these are compared to mortality rates in other groups (Jannerfeldt & Hörte 1988:679). The median age of death trends are an indication of the changes that take place over time in premature mortality. The median age of death is an easy indicator to calculate. It does not require standardisation and is useful for determining the impact of a disease on premature mortality. Premature mortality is defined as the potential years of life that are lost for whatever reason (Jannerfeldt & Hörte 1988:678.) Crum et al. (2006:195) have demonstrated that an increase in age at the time of death from 37 to 40 years has coincided with an increased access to ART.

In summary, the introduction of ART has resulted in a profound overall decline in HIV-associated morbidity and mortality (Kessler 2003:S101). The impact of increased access to ART in high HIV-prevalence settings even with low coverage has been an increase in patient survival rates and reduced overall mortality rates. It is therefore imperative that increased access to ART in high HIV-prevalence settings should be able to be directly related to increases in survival through the median age at the time of death and life expectancy if ART provision is to be considered a success. This is why the researcher in this study has focused on the overall impact how an increased access to ART has influenced morbidity and mortality rates in a rural setting in Uganda.

2.7.3.4 Demographic impact of antiretroviral treatment

The review of mortality trends has demonstrated the demographic patterns inherent in mortality. Crum et al. (2006:195) have also reported that despite increased access to ART, the sex or race of patients who have died has not substantially changed among HIV-infected persons.

2.8 GLOBAL FOCUS ON HUMAN IMMUNODEFICIENCY DISEASE

The Millennium Development Goals (MDGs) have further emphasised the need to control the HIV epidemic and their overall goal is to reduce morbidity and mortality and thus foster the welfare and sustained development of their individual countries (UN 2008:28). The sixth goal of the MDGs is to “combat HIV/AIDS, malaria and other diseases”, and the HIV-related target for this goal is to halt and begin to reverse the spread of HIV/AIDS by 2015 (UN 2008:28). The PEPFAR and GFATM are massive responses to the ravages of the HIV/AIDS plague (Abdool Karim & Abdool Karim 2003:1499; The GFATM 2007:6). WHO, The European Commission and other bilateral funding agencies such as the the Japanese International Development Agency (JICA) have been rolled out to tackle the impact of HIV/AIDS in sub-Saharan Africa as a medical emergency and as a development issue with significant macro- and micro-level economic impacts (Whiteside 2005:408).

Increased access to these funds has made a significant impact on HIV/AIDS and on the overall mortality caused by HIV/AIDS (McCarthy 2007:1155). These programmes have not only focused on HIV/AIDS but also on general and specific improvements to all the health delivery systems that operate in affected countries. Jaime Sepulveda has written: “PEPFAR has demonstrated what many doubted could be done, namely that HIV/AIDS services can be scaled up rapidly in countries with severe resource constraints and other daunting obstacles” (McCarthy 2007:1155).

The five-year US\$15 billion initiative was launched as an act of Congress in 2003. Most of PEPFAR resources go to the 15 so-called focus countries that have been hardest hit by the ravages of the epidemic. These include the 12 sub-Saharan African countries (of which Uganda is one), as well as Guyana, Haiti and Vietnam (McCarthy 1155.) Among PEPFAR's five-year performance targets are those that contemplate the provision of

antiretroviral therapy to two million people with HIV/AIDS, and consequent prevention of seven million HIV infections. According to the Office of the Global AIDS Coordinator (OGAC), PEPFAR had, by September 2006, provided antiretroviral therapy to 822 000 adults (McCarthy 1155).

UNAIDS has guided and co-ordinated the global response while governments and the variety of non-government organizations and initiatives funded by civil society have been funded to implement programmes that will mitigate the impact of HIV/AIDS. The provision of ART to two million people in the 15 most HIV/AIDS-affected countries has, because at the PEPFAR funding alone, already made a significant impact on morbidity and mortality trends, especially in sub-Saharan Africa. The GFATM estimates that two million lives have been saved through the programmes that it supports, and that an estimated 100 000 lives are saved every month (GFATM 2007:7)

By June 2008, the GFATM had committed US\$11 billion and disbursed US\$6 billion to mitigate the impact of the three diseases that are especially associated with HIV/AIDS. By the end of 2007, The Global Fund delivered ART to 1.4 million patients (GFATM 2007:7).

The global response to HIV has therefore had – and will continue to make – a significant impact on HIV/AIDS mortality trends. The envisaged impact of ART is reduced morbidity and mortality. This is the most important goal for all programme implementers and should be the focus for all future mitigation interventions.

2.9 THE JUSTIFICATION FOR MONITORING MORTALITY TRENDS

Over the years, a significant amount of attention has been invested in monitoring child morbidity and mortality in sub-Saharan Africa while minimal emphasis has been focused on adult mortality trends. There are, however, numerous indications that adult mortality rates are high and that they require the most meticulous and comprehensive attention and monitoring (Dudgeon, Novoa, Macassa Sacarlal, Black, Michaud & Cliff 2001:546). There is, for example, a critical lack of accurate mortality data from the countries of sub-Saharan Africa (Corbett et al. 2002:2185). The challenges in Uganda include severe limitations in the independent evaluation of the impact of health interventions on mortality. The WHO recommends sustained and regular tracking (monitoring) of the

causes of death and mortality (WHO 1999:17). This setting up of surveillance and monitoring standards is one of the most critical components of any national surveillance plan and needs to focus on a list of diseases that urgently need the most careful surveillance (WHO 1999:10). This list of diseases or conditions to be considered for careful monitoring and surveillance should be as short as possible and should be based on the following simple guidelines:

- Does the disease create high impacts in terms of morbidity, disability, mortality?
- Does it have significant epidemic potential?
- Is it a specific target for a national, regional or international control programme? (WHO 1999:10). (Thus, for example, is the disease targeted for surveillance by a WHO Regional Plan or is it a notifiable disease in terms of WHO International Health regulations)?
- Will the information that is being collected enable health care professionals, researchers and administrators to promote significant public health action?

In the first place, if one considers the WHO criteria mentioned above, it is indubitable that HIV/AIDS results in high morbidity and mortality rates and is therefore a disease that should be considered for intensive routine mortality monitoring. Secondly, HIV/AIDS is currently a plague of pandemic proportions, and this alone justifies specific and concerted efforts to track its impact on communities and on efforts to assess the interventions that are designed to mitigate the effects of the disease. Thirdly, HIV/AIDS is a targeted disease, both at regional and global levels of the WHO. Fourthly, detailed and accurate data about trends in HIV/AIDS mortality and the impact of interventions such as free access to antiretroviral treatments need to be made because they constitute the necessary evidence on which health-related decision making has to be based. This kind of evidence is needed because it guides and determines the design and implementation of effective public health interventions that will further reduce the impact of HIV/AIDS. Lastly, since mortality trend data is routinely collected in all hospitals and clinics, it should be easily obtainable and analysed.

With regard to HIV/AIDS, WHO recommends a routine monthly reporting of aggregated data from a peripheral to an intermediate level and a quarterly reporting of mortality reports and statistics (WHO 1999:28). This reporting requirement has been inadequately accomplished in low-resource settings. In sub-Saharan Africa, mortality

estimates are based on household surveys or information from replies to census questions (McMichael et al. 2004:1156).

The regular monitoring of mortality trends guide programme managers as they attempt to determine the magnitude of the problem, to plan public health measures, to plan health care services and supplies, to assess the impact of the disease on clinical services and to validate the accuracy of HIV surveillance data (WHO 1999:28). The WHO Resolution AFR/RC48/R2 of the Regional Committee recommends that member states should make effective use of epidemiological data in decision-making, priority setting and resource allocation (WHO 1999:18.)

In Uganda, as in other sub-Saharan Africa countries that monitor the epidemic from the health facilities that provide ART, the focus is on the number of patients enrolled in ART programmes, the number of patients who have been screened for ART, the number of patients who have attended follow-up clinics, and on the number of treatment defaulters. Other parameters that are recommended include descriptive information about adherence, the nature and frequency of side effects and other toxic effects, the extent of treatment failures, and the efficiency or otherwise of drug procurement and laboratory services (Ministry of Health – Government of Uganda 2003b:26.)

Apart from this ongoing research activity, the Uganda HIV/AIDS programme is severely deficient in monitoring hospital morbidity and mortality trends as a measure of monitoring the progress that is being made towards meeting the MDGs (UN 2008:28).

Since Uganda has experienced a dramatic increase in access to ART, this increased access to ART should result in a dramatic reduction in morbidity and mortality which should also be appreciated and carefully documented at the level of hospitals and clinics. It is also notable that the ART programmes in Uganda and sub-Saharan Africa falls generally short of the WHO recommendations for monitoring morbidity and mortality trends of serious epidemics such as HIV/AIDS so that mortality data can be used as a basis for critical programmatic decision making. Even though free ART may be become widely available, other significant factors that fuel the spread of HIV/AIDS and that act as obstacles to the reduction of morbidity and mortality, should be carefully evaluated if health-care administrators wish to sustain a permanent improvement in the treatment of people who are living with HIV/AIDS.

In order to optimize the benefits of ART, a much greater focus should be invested in the meticulous, comprehensive and ongoing monitoring of morbidity and mortality trends. That is why the researcher undertook this study in the first place. This study focused on the mortality trends in a rural setting in Uganda and the findings provided an insight on what is happening in and in similar settings as well as indications of what needs to be done.

2.10 BARRIERS TO THE SUCCESS OF ANTIRETROVIRAL PROGRAMMES

Since ART services are currently provided free of charge in many developing countries, the challenge is to ensure that HIV-positive patients who are in need of treatment will gain access to ART treatment before the HIV disease reaches an advanced stage. By doing this, the health care services of sub-Saharan countries should be able to reduce the rates of morbidity and mortality. Delayed access to ART may be caused by an inadequate perception of the risks involved and an inadequate perception of the severity of AIDS as a lethal disease. Other barriers to ART access include a lack of ARVs in facilities, and certain demographic, social, psychological and structural barriers. But all these factors are beyond the scope of this dissertation.

2.10.1 The cost of antiretroviral treatment as a barrier to access

The single most important barrier that disrupts access to and adherence to ART is poverty. This implies that it is financial limitations that contribute most frequently to treatment interruptions (Wilson & Fairall 2008:485). In Botswana, for example, the impacts of various factors on adherence were modelled, and when cost restrictions were removed, adherence to ART was projected to increase from 54% to 71% (Wilson & Fairall 2008:485). It is therefore expected that by providing free access to ARVs at the point of service, more HIV individuals will be able to access ART at an early stage (before the disease advances to its terminal manifestations), and that sufferers will experience fewer interruptions in treatment because of a lack of medicines caused by their inability to afford the costs related to ARV access. Interruptions in the supply of ARVs are caused by an absence of medicines in a health facility or an inability of a patient to access ARVs in good time, resulting in periodic breaks in ARV regimen adherence, and result in poor treatment outcomes.

Wilson and Fairall (2008:487) have also reported *stigma* as a key barrier to access. The existence of a stigma surrounding HIV/AIDS and its implications, are creating significant challenges to the provision of antiretrovirals in the public sector. The provision of free antiretrovirals without a parallel effort to reduce the effects of social, religious and community stigma issues in public facilities will significantly hamper the achievement of universal access (Wilson & Fairall 2008:487).

The cost of access to ART treatment and care consists of a number of required expenditures that include the cost of appropriate food for good and healthy nutrition, the cost of transport (especially in the case of rurally based patients), and the cost of paying for the treatment of treatment for other opportunistic infections. All these barriers are created by the effects of poverty and can effectively negate the achievement of the benefits of ART for HIV-infected patients.

2.10.2 Poor adherence to antiretroviral treatment regimens as a barrier

Adherence to the requirements of a treatment regimen is a critical determinant of the reductions in morbidity and mortality even after free access to ART. If a patient manages to access treatment but, for one reason or another, does not adhere meticulously to the requirements of the dosage regimens that are optimal for the success of the treatment, treatment outcomes will be poor and morbidity and mortality trends will thus either stagnate or increase. “Effective ART programmes require high adherence to medication” (; Lieb, Brooks, Hopkins, Thompson, Crockett, Liberti, Jani, Virkud, West & McLaughlin 2002:251; Mermin et al. 2008:752).

2.10.3 Overextended health systems as a barrier

The availability of free access to ART in conjunction with inadequate systems and resources to cater for the increased number of patients that desire to access it, has led to severe strains on the already profoundly overextended health care systems of many sub-Saharan African countries (Abdool Karim et al. 2005:43). The overloading of the health care system because of an increasing demand for HIV/AIDS care and support services has already compromised the quality of service delivery and of health service delivery in general in many other countries mentioned in this study (Uganda AIDS Commission – Government of Uganda 2008:40). Because of numerous problems

associated with the time the delivery of services to PLWHA, many overextended and under-resourced health care systems are already in themselves a significant barrier to the successful delivery of ART to those who need it. Because of the very large number of patients and the lack of capacity of many health systems to cope with them (Abdool Karim et al. 2005:43), waiting times are frequently long, privacy is compromised, and a proper responsiveness to the demands of PLWHA is far from what it should be. McCoy, Chopra, Loewenson, Aitken, Ngulube, Thabale, Muula, Ray, Kureyi and Ijumba (2005:18–22) have reported a number of obstacles that already been encountered in the campaigns to rapidly expand access to antiretroviral therapy in sub-Saharan Africa. These obstacles include undesirable opportunity costs, the fragmentation of health systems, the disintegration of many health systems under the impact of pressures of which they cannot cope, the steady worsening of health care inequities, and poor and unsustainable treatment outcomes.

2.10.4 Human resource challenges as a barrier

Human resource constraints also pose a significant barrier to ART access. The skills of the available doctors, nurses and other health workers that are required to administer successful programmes of free ART delivery fall far short of what is required to deliver an above-average health service in many countries of sub-Saharan Africa including Uganda (McCoy et al. 2005:18). In Malawi, there is only one physician for every 50 000 to 100 000 people (Aitken & Kemp 2003:18; Mills, Schabas, Volmink, Walker, Ford, Katabira, Anema, Joffres, Cahn & Montaner 2008:685). In Uganda there is only one physician per 12 500 members of the population, one nurse for every 1 818 people, and one pharmacist per 33 300 members of the general population (Mills et al. 2008:686). As the burdens of HIV-related disease increase, the capacity of health care systems in sub-Saharan Africa to deliver quality care to PLWHA has been severely compromised (Fabiani et al. 2003:62). The increasing migration of health care workers to countries in which they can improve the prospects for their careers, is also projected to lead to numerous further reductions in the required number of health workers who are available to manage the HIV/AIDS pandemic and the projected number of patients with HIV infection who will be in need of care. Projections show that as this process of attrition continues, the number of patients for each available physician will increase from 9 000 (in 2006) to 26 000 (in a 2012) (Mills et al. 2008:687).

2.10.5 Other barriers and obstacles

Other challenges include an inadequate state of preparation and understanding on the part of communities and patients, an erratic and unsustainable supply of the necessary medications, and inadequate levels of training and support for health care providers (Stevens, Kaye & Corrah 2004:280). These barriers have resulted in a lack of monitoring of poor adherence to treatment, and an increased threat of the development of drug resistance (Stevens et al. 2004:280).

While an uninterrupted supply of ART increases the prospects of patient survival and reduces morbidity and mortality among HIV/AIDS patients (Lieb et al. 2002:356), barriers that interrupt and compromise access to ARVs contribute to unchanged or the increasing morbidity and mortality rates that are associated with HIV disease – despite the availability of free access to ARVs. These are but a few of the many barriers that prevent timely access to ART before advanced HIV disease (AIDS) reaches its final outcome. All of these barriers significantly deter timely access to ART, proper adherence to treatment programmes and the necessity for strict adherence to HAART dosage regimens. The major barriers thus include the cost of ARVs and other related costs, the stigma that is still widely prevalent in many countries, and overloaded health care facilities that are unimaginably overextended and under-resourced. Therefore, despite free access to ART in many of the health facilities in sub-Saharan Africa, they are still other barriers that prevent access to these free ARVs that so important in their effects that they cannot be overlooked or ignored in the delivery of ART. All of these barriers to access can result in increasing or stagnant mortality trends. Aspects of these barriers were included in the analysis of the study results and formed a critical component of the discussion and conclusions.

2.11 MORTALITY TRENDS IN THE ERA OF ANTIRETROVIRALS

In the 1980s and 1990s, an HIV-positive status was considered to be a death sentence and was regarded as a deadly disease in Uganda (Teja et al. 2007:555; WHO & UNAIDS 2002:3). Since AIDS was a disease for which there was no known treatment, it was well known that any individual who had been infected with HIV would finally succumb to the effects of AIDS and death. It is therefore very clear to HIV-positive

patients in Uganda that AIDS is a very serious disease that may, if untreated, ultimately lead to death (Ministry of Health – Government of Uganda 2006:44).

While ART delays the progression of AIDS and reduces the risk of death for HIV-infected patients (Wood 2008:504), mortality and morbidity trends in high-prevalence settings even with free access to ARVs, are affected by a number of factors. These barriers and obstacles result in late access to ART or to no access to ART at all. While ART significantly reduces mortality among HIV-positive individuals, mortality has been noted to be high in the first six months of treatment (WHO 2006b:25). In addition to this, studies have also shown that ART does not *completely* prevent the development of the clinical symptoms of HIV-related illnesses, and that an increased risk of death is especially evident among patients who have begun treatment when HIV disease has reached an advanced stage and their immune systems have already been severely depressed (WHO 2006b:25; Wood 2008:504).

A review of HIV-related mortality trends of patients on ART in sub-Saharan African countries revealed that the mean or median time to death was 57-182 days after the commencement of treatment, and that 55-100% of deaths occurred within the first six months of treatment (Sutcliffe, Van Dijk, Bolton, Persaund & Moss 2008:484-85). It is therefore valid to conclude that the mortality of patients on ART in developing countries is especially high during the first year of ART treatment. Therefore, since a significant proportion of HIV patients access ART too late (i.e. when HIV disease has already reached an advanced stage), mortality trends in hospitals may remain unchanged (stagnant) or may even increase.

It is therefore imperative to ensure that HIV positive patients access treatment *before* the appearance of advanced forms of HIV-related illnesses if they are to receive the therapeutic benefits of ART. Once patients had commenced on treatment, they should faithfully adhere to all treatment requirements for the remainder of their lives in order to ensure that they receive the optimum benefits that ARVs are able to confer. In order to determine the impact of ART, there is therefore an urgent need to monitor morbidity and mortality trends as completely and thoroughly as possible in the prevailing circumstances.

2.12 SCENARIOS OF EXPECTED MORTALITY TRENDS

The researcher has posited three mortality and morbidity trends that will occur in any rural setting in which patients have access to an antiretroviral treatment programme. These trends are all based on the factors mentioned above – all of which are factors that can either negatively or positively affect morbidity and mortality rates. The three scenarios are trends that display increasing, stagnant and reducing patterns of morbidity and mortality.

The first scenario involves an increasing trend in admissions and mortality that may be caused by inadequate ART coverage for PLWHA or by late access to ART by people living with HIV/AIDS, or the effects of an inability to tolerate the toxicity that is associated with some ARVs (Mocroft et al. 1999:1260). Increasing mortality and morbidity trends are an indication that in the absence of other factors that significantly affect mortality patterns, the introduction of free access to ART in a rural setting has not significantly affected mortality and morbidity trends in a rural setting.

The second scenario is a stagnant morbidity and mortality trend that may be caused by a number of factors that indicates the absence of any impact of ART on mortality rates. Stagnant mortality trends indicate a mortality rate which is equal to the population rate growth rate. Alternatively, stagnant trends may indicate that the programme did indeed successfully reach all PLWHA in need and thus stabilised mortality trends with a constant balance of new patients and mortality.

The third scenario involves a reducing morbidity and mortality trend which is largely caused by a successful ART programme and patients who are able to enrol in good time with an efficient and well-functioning ART programme, with the availability of treatment to those in the community who need, and good adherence rates. The third scenario is the best-case scenario that programme managers can hope to expect.

Apart from gross mortality trends, a review of mortality data also reveals a number of aspects of mortality that guide programme decision-making. In a study of “comparisons of causes of death and mortality rates among HIV-infected persons”, the annual death rate peaked at 10.3 per 100 patients (1995) and then steadily declined to 2 deaths per 100 persons in 6 years during the ART-era (Crum et al. 2006:195). It is a recognized

fact that trends in hospital admissions and trends in mortality are likely to reflect the healthiness of the population in general (Mocroft et al. 1999:1260).

The most important focus of this study was to determine the morbidity and mortality trends in the particular rural setting and has already been described. A clear understanding of these trends are needed to inform health care decisions and guide research activities that will provide answers to why these trends occur in the way that they do, and to ultimately reduce overall morbidity and mortality rates. It was thus the task of this study to determine which of the three scenarios was actually taking place in the rural hospital in which the study took place.

2.13 RESEARCH GAPS

It is by means of this literature review that the researcher has noted that without a reliable comparative morbidity and mortality trend analysis before and after free access to ARVs available in a hospital setting, HIV programmes are in many ways working in the dark. In such circumstances, health programme managers become lost in fairly short term results or process indicators such as the number of HIV patients who had commenced ARV treatment, and they unfortunately remain ignorant of the significance of many critical short- and long-term impact indicators.

After more than four years of free access to antiretroviral treatment in public facilities in Uganda and in sub-Saharan Africa, the researcher undertook a critical review of the morbidity and mortality trends in the hope that these could be extrapolated to the larger picture in order to inform decisions about the arrangements that will be made for ART programming in the years to come. Such information will ensure that patients receive the optimal benefits that are available to them through the health care systems that have the responsibility of reducing the burden of disease and mortality among their clients. "Our ability to define and monitor the full effect of the HIV epidemic is seriously compromised by scarce research and routine surveillance data for most infectious diseases in Africa" (Corbett et al. 2002:2185). These researchers have recommended that "surveillance of disease trends and research into infectious disease control should be priorities in countries severely affected by HIV-1 and public health investment and standards should be enhanced to cope with the new realities of infectious disease control since the HIV-1 epidemic" (Corbett et al. 2002:185).

There is an inadequate amount of reliable and comprehensive information in sub-Saharan African countries about morbidity and mortality trends that will enable health care administrators adequately to make sound evidence-based decisions about cost effective interventions that will be able to reduce the impact of HIV/AIDS.

2.14 CONCLUSION

This chapter reviewed the literature about HIV disease, the impact of HIV disease globally and in sub-Saharan Africa in particular, the numerous factors associated with the provision of ART, and the interventions that Uganda has implemented to contain the epidemic. It is, however, noteworthy that mortality trends in Uganda and a number of other low-resource settings have been inadequately monitored over the years. In this era of ART access, mortality and morbidity trends are vital indicators for determining policy and for ensuring the success of programmes.

Chapter 3 deals with the methodology that the researcher used for prosecuting this research.

CHAPTER 3

Research methodology

3.1 INTRODUCTION

Research can be defined as “the systematic and rigorous process of inquiry which aims to describe phenomena and to develop and test explanatory concepts and theories” (Bowling 2007:1). Research methods or techniques consist of various methods of data collection such as, individual face-to-face interviews, focus group interviews, structured questionnaires, the examination of historical records, and any other instrument or technique that the researcher deems appropriate for the collection of data (Bowling 2007:436). This chapter describes the research design, the approaches and the methods that the researcher applied to achieve the aims of this study. His methods of investigation included a careful review of the whole study population, the determination of a sample by the application of a particular sampling method, the collection and analysis of data, the abdication of techniques to ensure validity and reliability, and the use of widely accepted ethical principles to guide all aspects of the research. His research methodology also comprised a research design, the identification and description of the study population, the use of various data collection instruments and techniques, the application of the ethical principles that are recommended by the university throughout the course of the research, an analysis of the raw data, and the use of various methods to the results obtained in to make extrapolations and projections from these results.

The methodology of any particular research project guides the researcher and enables the reader to understand and appreciate why the research progresses or progressed in the way that it does or did.

The most basic method that the researcher adopted in study was deductive reasoning or the deduction approach. Deduction in research refers to the process whereby one begins with the formulation of one or more general ideas or hypotheses, and that one uses these hypotheses to develop a more specific and exact theory , after which one proceeds to test the hypothesis in terms of the data that one has collected(Bowling

2007:118; Trochim 2006a:[1]). The deductive approach in research is sometimes referred to as a "top-down" approach (Trochim 2006a:[1]) (see figure 3.1).

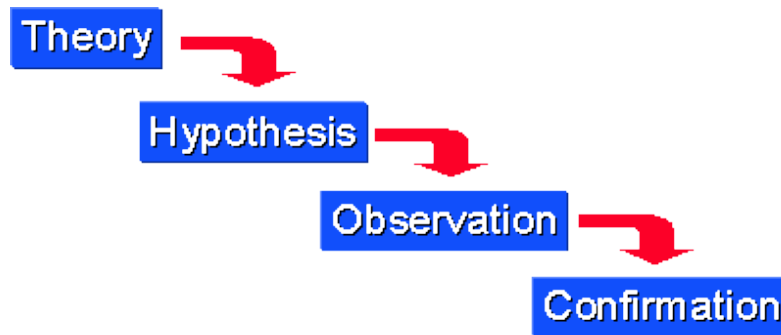


Figure 3.1: The Flow of deductive thinking approach in research

(Source: Trochim 2006a:[1])

The researcher therefore approached his research topic by making use of a deductive method which is illustrated in figure 3.1 (above).

Theory has been defined as “the analysis of a set of facts in their relation to one another or a *belief, policy, or procedure proposed or followed as the basis of action or a plausible or scientifically acceptable general principle or body of principles offered to explain phenomena*” (Merriam-Webster Online Dictionary 2009e:[2]). Theory was also defined by Hornby (2005:1532) as “a formal set of ideas that are intended to explain why [something] happens or exists”. In this study, the initial overall theory that guided the progress of research was that a high rate of HIV infections in a particular population will always be associated with a high degree of adult morbidity and mortality, and that the widespread use of ARVs among HIV-infected people in such a population will significantly reduce the rates of adult mortality and morbidity. This theory has in fact been backed up reports in the literature on the topic (see section 2.7 for a detailed discussion of this evidence). When researchers utilise a deductive approach in research within the broader framework of a particular evidence-based theory, one will have opportunities to develop one or more hypotheses that will either confirm or disconfirm reports from earlier research. It is in this way that research develops and is refined by

the results of other research that confirms the original premises or modifies the terms and assumptions which frame the original theory and its findings.

A **hypothesis** may be defined as "an idea or explanation of [something] that is based on a few known facts but that has not yet been proven to be true or correct" (Hornby 2005:736). A hypothesis may also be defined as a "proposition [that is] tentatively assumed in order to draw out its logical or empirical consequences and [to] test its consistency with facts that are known or may be determined" (Merriam-Webster Medical Dictionary 2009f:[1]). The main hypothesis of this study was that if free ARVs were introduced into a rural hospital in a high-HIV prevalence setting in Uganda, the prevailing morbidity and mortality rates would be reduced (and that this, if represented graphically, would be clearly visible in a downward trend). The hypothesis that was tested in this study was therefore framed by the researcher in the following words: "*The introduction of free antiretroviral treatment in a rural hospital leads to a reduction in overall morbidity and mortality rates.*"

This study therefore commenced with a *theory-specific hypothesis* that the researcher tested by collecting a large amount of information about adult morbidity and mortality trends from the specific group of patients who attended a particular hospital in a rural setting in Uganda over a particular period of time. The research extended over a period of years which included three years in which free antiretroviral (ARV) treatments were not available, and three years in which free antiretroviral treatments were available. This fundamentally important variation in the conditions that the patients in the sample encountered in the rural hospital in which the study was performed, allowed the researcher to make significant conclusions from the influence of free ARV on a large sample of HIV-infected patients. The researcher compiled as much relevant information as he could obtain from all the mortality records in the hospital. These records included ward registers, death certificates and patient files, and the hospital authorities made them freely available to him for the purposes of his research. Through the information that he assembled and collated in this way, the researcher was able to construct further **observations** that helped him to refine his theories in such a way that would be more effective in either confirming or disconfirming his hypotheses. This process enabled the researcher to test his hypotheses by measuring them against the specific data and information that he was able to assemble, and this resulted in the confirmation or modification of his original theories (Trochim 2006a:[1]). "Deductive reasoning is more

narrow in nature and is concerned with testing or confirming hypotheses.” (Trochim 2006a:[1]).

3.1.1 Study variables

A **variable** is defined as a characteristic of an individual, object or unit that can be measured or observed, and that has the capacity to vary in extent, quantity or quality among the individuals or units that are being studied or examined (Creswell 2003:93; Rudestam & Newton 2007:22).

An **independent variable** can be defined as a variable that causes or influences or affects a specific outcome (Creswell 2003:94; Somekh & Lewin 2005:216). The independent variables in this study included the primary and associated causes of death, age, gender, the length (in a number of days) that patients remained admitted to the hospital before their death, and the out-of-pocket payments that patients or relatives made for health services in the hospital under study. A **dependent variable** can be defined as a variable that an independent variable causes to change. Dependent variables are therefore the outcomes of the effects of independent variables (Creswell 2003:94). The dependent variables in this study include the number of admissions, the number of patients on ART, the extent of ART coverage among the population sample that the researcher was studying, and the number of deaths that occurred in the hospital (which, in this study, are represented as the number of deaths per 100 patient admissions).

Table 3.1: Variables, research questions and data collection items

Variable name	Research question	Item on the data collection tool and the tool that was used to compile the data
Dependent variables	What is the overall adult hospital mortality trend in reference to the pre-free ART period and the post-free ART period? And what is the projected trend? <ul style="list-style-type: none"> • Accomplished by analysing mortality rate (number of deaths per 100 admissions) and by comparing these mortality trends with the estimated ART coverage 	Data collection tool B: <ul style="list-style-type: none"> • Number of adult admissions per month (an “adult” in Uganda being defined as a person 15 years old or older) • The cumulative number of patients on ART per month • The total number of deaths per month
	What is the overall effect of free ART access on hospital mortality trends? <ul style="list-style-type: none"> • Accomplished by analysing the mortality rates and trends (the number of deaths per 100 admissions) and by comparing them with the estimated ART coverage 	Data collection tool B: <ul style="list-style-type: none"> • The number of adult admissions per month • The total number of deaths per month
Independent variables	To what extent can adult hospital mortality trends be correlated with factors such as age, gender, cause of death, length of stay in hospital (i.e. the number of days the patient is admitted in hospital before death), the out-of-pocket payments (or health user fees that are usually paid by relatives) in the pre-free ART era and the post-free ART era?	Data collection tool A <ul style="list-style-type: none"> • The cause/s of death • The age of the patient • The gender of the patient • The average length of stay in hospital (abbreviated as “ALOS”) or the number of days the patient remains admitted to hospital before death • The out-of-pocket payments (user fees) that are paid by relatives

Table 3.1 (above) summarises the variables under review in this study (see section 3.1.1 for a detailed description of the content of table 3.1) according to the research questions under investigation. This table also indicates the specific tool that the researcher utilised to collect this information. This table lists the variables, the study questions and the study instruments. On the basis of these study variables, the researcher analysed the data that he collected and thus provided considered answers to the research questions.

3.2 RESEARCH DESIGN

Research design is “the strategy of research” (Bowling 2007:436) because it indicates how the sampling is conducted, how the variables are operationalised and measured, and what kind of analysis will be conducted.

“Research design provides the glue that holds the research project together. A design is used to structure the research, to show how all of the major parts of the research project – the samples or groups, measures, treatments or programs, and methods of assignment – work together to try to address the central research questions” (Trochim 2006b: [1]).

Research design may also be defined as the “plan to be followed to realize the research objectives or hypothesis. It [the research design] represents the master plan that specifies the methods and procedures for collecting and analyzing the required information” (Van Wyk 2005:82). A specific research design guided the researcher in the overall planning and implementation of the study in order to accomplish the research goals.

The researcher chose a quantitative, retrospective, descriptive and cross-sectional research design for this study to enable him to provide a detailed description of the adult mortality trends both before and after the introduction of free antiretroviral therapy (ART) into the particular rural hospital in Uganda.

3.2.1 Quantitative study design

A quantitative research design provides a “quantitative or numeric description of trends, attitudes, or opinions by studying a sample of that population” (Creswell 2003:153). A quantitative study design provides a sound basis for generalising the results obtained from a particular study population to general population that it represents (Creswell 2003:153). The assumptions of a quantitative methodology are justifiable in terms of a positivist epistemology that assumes that the nature of the reality that human beings experience is objective and external to the human mind, and that it can be expressed numerically. It therefore emphasizes the dependability of measurement and quantifiability, and seeks to determine invariable relationships between similar phenomena (Glatthorn & Joyner 2005:40). In quantitative studies, the “theory becomes the framework for the entire study, an organising model for the research questions or hypothesis and for the data collection procedure”(Creswell 2003:125). In addition to this, “the researcher advances theory, collects data to test it, and reflects on the confirmation or disconfirmation of the theory by the results” (Creswell 2003:125).

The quantitative information in this study was gathered by the researcher and his assistants from a structured audit and review of all the hospital's patient records in the period covered by the study. He then analysed the data thus obtained by making use of the Epi info program and determined frequencies for the responses to all the items listed in the audit, collated these in the results section of the report, and used the information collected in this way as a basis for further discussion, analysis and conclusions.

3.2.2 Descriptive design

Descriptive design "is constructed to answer who, what, when, where and how questions." (Van Wyk 2005:86). Descriptive researchers therefore observe, then explore and describe key aspects related to a situation as it occurs (Polit & Beck 2006:192). In descriptive research, a researcher acquires a basic understanding of the underlying relationships that prevail in the problem under study, and uses structured and quantitative methods such as the audit tools that were used in this study (Van Wyk 2005:86).

This study was therefore also descriptive in nature because it described a particular set of phenomena and their reported frequencies, and because it determined the averages and percentages pertaining to the characteristics of the population by examining a specific sample of that population (Glatthorn & Joyner 2005:103).

This study investigated and described adult mortality trends both before and after the introduction of free antiretroviral therapy in a rural hospital in Uganda in order to enhance scientific knowledge about the numerous unexplained factors and unanswered questions that pertain to this area of public health.

3.2.3 Cross-sectional studies

Cross-sectional studies require "the collection of quantitative data on at least two variables at one point in time and from a number of cases". [The] data are used to look for patterns of association or relationships either in the group as a whole (all cases) or in subgroups sharing characteristics or attributes" (Somekh & Lewin 2005:216). In this study, the cross-sectional study design was used to collect the necessary data from the

medical records department of the hospital about the death of all adult members of the population (an “adult” is defined in Uganda has been 15 years and older) over a six-year period from between June 2002 and June 2008.

3.3 POPULATION AND SAMPLE

The population is the entire set of individuals that have the same characteristic or set of characteristics in common.

3.3.1 Population

Population therefore refers to that conglomeration of individuals towards which the questions that motivate the research are directed (Bland 1995:27; Polit & Beck 2006:259). A *study population* may be defined as “the entire aggregate of cases that meet specified criteria” (Polit & Beck 2006:259) or the complete set of units that is being studied (Somekh & Lewin 2005:217). In addition to this, a population is also “an aggregate of people or objects” (Bowling 2002:176). The *study population* is the whole population group to which the results of a study will and should be generalized. In quantitative studies, the specific characteristics that delimit the study population are put into effect by means of eligibility or inclusion criteria (Polit & Beck 2006:259). In this study, the study population was the total number of adult deaths (including those that occurred in the facility and at home) that occurred in the district under study throughout the length of the study period.

3.3.2 Sampling frame

Sampling is defined as the process and techniques that are used to select a portion or a subset of the population called a *sample*, which will serve to represent the entire population (Bowling 2002:436; Polit & Beck 2006:260). Once the study population has been identified, the population from which the sample will be drawn is identified. The *sample size* is defined as the number of elements or subjects that are included in the population that will be studied (Polit & Beck 2006:267). The use of a representative sample in a study enhances the generalisability of the research results (Rudestam & Newton 2007:106; Polit & Beck 2006:268).

In general, a sample size increases in proportion to the population size and the sampling error decreases in proportion to the sampling size. The larger the sample, therefore, the smaller will be the sampling error because the sample becomes more and more representative of the population as its size increases (Polit & Beck 2006:268).

The sample selected for this study included all adult deaths among those who were admitted to the medical and surgical wards of the rural hospital as a subset of all the deaths that occurred in the district. Although the sample that the researcher used in this study is therefore representative of what happened in Mpigi district during the period investigated by the study, its results cannot be generalised to mortality trends across the rest of Uganda during the same period. These trends nevertheless remained pertinent to and indicative of what was happening in hospitals in similar settings in Uganda.

3.3.3 Sampling and sample

A *sample* “is a subset of a population selected to participate in a study” (Polit & Beck 2006:260). A sample may also be defined as “a finite part of a statistical population whose properties are studied to gain information about the whole” (Merriam-Webster's Medical Dictionary 2009f:[1]). In other words, a sample is a basic level or unit of investigation, or the representative unit of a population that one studies in order to appreciate and understand the population from which it is drawn (Somekh & Lewin 2005:218; Van Wyk 2005:340). In cases of finite resources, it is far preferable to study the whole population, but because finite resources do not occur, researchers tend to use a sample rather than the whole population “because it more economical and practical” (Polit & Beck 2006:260).

The two main concerns in quantitative studies are “how the sample is selected and how many elements [it possesses]” (Polit & Beck 2006:261). There are two broad sampling techniques that are used in quantitative studies, and they are “*probability sampling* and *non-probability sampling*” (Polit & Beck 2006:261).

In probability sampling, a researcher uses the technique of random selection to assemble a sample because this process or procedure ensures that the different units in the population will all have an equal probability of being chosen (Polit & Beck

2006:264; Trochim 2006c:[1]). But random selection and probability sampling are not used in to determine a sample in non-probability sampling. This does not necessarily mean that such a sample will not be representative of the general population, but it does imply that the sample will not be dependent upon the rationale of the probability theory (Trochim 2006d:[1]). In non-probability sampling, there is an insufficient amount of evidence to prove that the sample that is being investigated in the study is representative of the general population and that the results obtained can be generalised to it (Polit & Beck 2006: 261; Trochim 2006d:[1]). In non-probability sampling, a segment of the population is also very likely to be systematically intentionally or non-intentionally underrepresented. In this study, the researcher used the method of non-probability sampling because of convenience of access to the sample and because of the necessity to economise with the resources available for the study (Polit & Beck 2006: 264).

The researchers selected the Mpigi district by using the convenience or opportunity sampling method, which is a non-probability approach and which was suitable for this study (Creswell 2003:156; Somekh & Lewin 2005:219). He also used convenience sampling because the Mpigi district and the hospital in which the study took place were accessible, were ready and eager to participate in the study (Bowling 2002:187). Convenience sampling enabled the researcher to explore a number of complex issues, including health facility utilisation trends and certain features of out-of-pocket payments made by patients because both of these factors are of extreme importance for those who devise health policies at the level of central government (Bowling 2002:187).

Another reason why the researcher selected this particular hospital for review was, firstly, because approximately 40% of all the deaths that occurred in Mpigi district during the study period occurred in the health facilities of this hospital (this calculation was based on the patient workload that had to be serviced by the hospital staff). Secondly, because of the systems that had already been in place in the hospital from the period before the study commenced, the researcher expected that the mortality records would be more complete and accessible (in comparison to the records maintained by other public health facility settings). The assumption was therefore that the mortality trends in the hospital under study were indicative of the mortality trends in the district as a whole, and that the results of the study would be useful for helping health care administrators

and policymakers to plan effective interventions to reduce the rates of morbidity and mortality.

Because the number of deaths that occur in rural hospitals are relatively small, the researcher included all adult deaths of patients who had been admitted to the hospital during the study period in the sample.

The eligibility criteria for inclusion in the sample were therefore as follows:

1. They had to be adult deaths in the hospital (i.e. the deaths of individuals who were 15 years and older at the time of their demise).
2. The deaths had to have occurred in either the medical or the surgical wards.
3. The deaths had to have occurred during the period between June 2002 and June 2008.

The lack of information that was sufficiently reliable and comprehensive to capture the various aspects of life-threatening complications among pregnant women hindered the researcher's assessment of the impact of HIV infection on rates of maternal mortality and morbidity (Graham & Newell 1999:837). The researcher therefore decided to exclude maternal deaths from the sample because of the limited and often fragmentary nature of the information about the impact of HIV infection on maternal mortality (Khana, Pillay, Moodley & Connolly 2001:1861-62). An additional reason for this exclusion was provided by another study that investigated the effects of HIV/AIDS on maternal mortality in Malawi and Zimbabwe. It concluded that "further study is required to assess how HIV/AIDS affects pregnancy-related mortality rates" (Bicego, Boerma & Ronsmans 2002:1080). The researcher also excluded the deaths of any patients that occurred before admission to the hospital, and dead bodies that were admitted to the hospital for post-mortem or autopsy reports.

The study population was identified from a comprehensive examination of the hospital's patient records for the period under study. These records included death certificates, hospital inpatient case notes and registers.

Because the researcher utilised a non-probability convenience sampling approach in this study, the results were focused on the morbidity and mortality trends in the hospital

under study and are therefore only indicative of what was happening in similar hospital settings in rural areas in Uganda during the same period.

3.3.4 Estimation of sample size

The size of the sample is of major importance in conducting quantitative research and in evaluating the findings of quantitative research (Polit & Beck 2006:267). A sample is the group of elements or subjects that are selected to take part in or participate in a research activity as study subjects (Trochim 2006e:[2]). The researcher used the convenience sampling approach in this study because it provided an easy and cost-effective method of access to the study sample (Somekh & Lewin 2005:219).

Adult mortality in this Uganda setting refers to the mortality of individuals who were 15 years and older during the period of study (Uganda Bureau of Statistics, Government of Uganda 2006b:42), and they were the focus of this study. In Uganda, 50.6% of the population is either 15 years or older (Earthtrends 2003:[1]; The International Institute for Strategic Studies 2000:[1]; Uganda Bureau of Statistics, Government of Uganda 2006b:17). By September 2002, the adult (“15 years and older”) population in Mpigi district was estimated at 206 342, with an annual district population growth rate of 1.3% (Uganda Bureau of Statistics, Government of Uganda 2006b:47). By June of 2008, the estimated district adult population was 222 348. There is a distinct lack of information about the mortality trends in Mpigi district.

The crude adult mortality rate in Uganda is 8.8 deaths per 1000 population per annum (Uganda Bureau of Statistics – Government of Uganda 2006c:278). Thus an estimated 1 816 deaths occurred in 2002 while an estimated 1 957 deaths occurred in 2008 of individuals aged 15 years and older, in Mpigi district during the length of the study period. To estimate the number of deaths that occurred in the district during the study period, the researcher used an average of the estimated number of deaths at the beginning of the study period and at the end of the study period. During the period between 2002 and 2008, the researcher estimated that an annual average of 1 887 deaths occurred (this represents an assumption of an adult mortality rate of 8.8 deaths per 1 000 population per annum) of adults who were 15 years or older at the time of their death in the district. By extrapolating these assumptions to the total number of

adult deaths had occurred over the six-year study period, the researcher estimated that 11 316 deaths occurred during this time.

In a rural setting in Malawi, 47% of the adult deaths of individuals who were 14 years and older occurred in a health facility (Jahn et al. 2008:1606). Although the overall mortality data for the district was not available, the researcher assumed that the Malawi experience was similar to what was happening in Uganda at the time, and therefore estimated that 47% of the deaths (or fewer) had occurred in health facilities.

In 2007/08, the estimated population of Mawokota South health sub-district was 99 607 (Lumala 2008:9,10). An estimated 50.6% (50 401) of these inhabitants were adults (Uganda Bureau of Statistics, Government of Uganda 2006b:17). With an adult crude mortality rate of 8.8 deaths per 1 000 of the population, an estimated 444 adult deaths occurred in the health sub-district per annum. Therefore, over the six-year period of the study, an estimated 2 664 deaths occurred in health facilities in the health sub-district.

To determine the size of the sample size, the researcher assumed that the Mawokota South health sub-district adult population of 50 401 represented the population size (N). Because of the inadequacy of accurate information about the prevalence of the adult death rate in Mawokota South, the researcher hypothesized a percentage (%) frequency of adult deaths in the population (p) at 50% \pm 5. Since the confidence limit that he used to determine the sample size as a percentage (%) of 100 (absolute \pm %) (d) was 3%, the confidence limit was 97%. By using this technique, the sample size (n) at a 97% confidence level was 467 deaths. During the study period, 561 deaths occurred in the hospital and therefore, all deaths in the hospital were included in the study (no sampling was carried out). The design effect (DEFF) of 1 was used for the calculation of the sample size (OpenEpi 2009:[1].)

The equation that the researcher used to determine the sample size was:

Sample size $n = [DEFF * Np(1-p)] / [(d^2 / Z^2(1-\alpha/2)^2 * (N-1) + p^*(1-p)]$ (OpenEpi 2009:[1]).

In order adequately to determine the overall mortality trends in the hospital, all adult deaths (i.e. those of individuals who were 15 years and older), and the death of all individuals who were admitted alive but who later died either in the surgical or medical

wards during the study period (July 2002 to June 2008), were included in the study sample.

On review of the medical records, 17 of the 561 records were considered too incomplete to be included in the analysis. Seventeen of the patient records were too incomplete or fragmentary to be included for the purposes of this study, and were therefore excluded from the analysis. The sample therefore ultimately comprised 544 deaths, which represented 3.9% of all the deaths that were estimated to have occurred in the district during the study period and 20.4% of all the deaths that were estimated to have occurred in the Mawokota county health facilities during the study period.

The deaths that were analysed in this study therefore met the requirements of the sample size of the study at a 97% confidence limit and the results are thus representative of mortality patterns in Mawokota South health sub-district.

3.4 DATA COLLECTION INSTRUMENTS

Measurement is the process of “observing and recording the observations that are collected as part of a research effort” (Trochim 2006f:[1]). Two structured data abstraction/audit tools enabled the researcher to collect and analyse the data in a quantitative manner. The data collection instruments comprised two data collection tools (see Annexure 1 and Annexure 2). The data was identified, examined and collated from the hospital’s patient records by means of a data sifting and “mining” process. Data sifting is the process of selecting the most important information that is embedded in records for purposes of analysis (Van Wyk 2005:486). In quantitative studies, research data is collected by using structured instruments that yield numerical and/or statistical data (Creswell 2003:18). The data was collected in terms of a structured plan that indicated who, when and how of the data collection process. Structured methods yield data that is relatively easy to quantify and analyse. Structured methods also impart objectivity to data that is collected by eliminating bias that is caused by a researcher’s personal feelings, assumptions or beliefs (Polit & Hungler 1995:311).

An audit tool was designed by the researcher for the study in order to compile a case-by-case summary. Data collection tool A collected information about the following facts: the date of admission, the date of death, the cause of death, the primary cause of

death, the associated cause or causes of death, the gender of the patient, the hospital ward in which the patient died, the patient's age at the time of death, the patient's HIV status (if this had been indicated in the records), and history of the ART treatment at the patient had received from the hospital (as indicated by the records). On the basis of the diagnosis and established cause of death in each case, all deaths were classified either as HIV-related or non-HIV-related or under the category of "HIV status undetermined".

Data collection tool B (Audit tool B) consisted of six templates that the investigators used to compile a summary of cumulative monthly figures of adult patients on ART, the ARV supply records, and all hospital admissions and deaths from between June 2002 and July 2008.

All the information collected by means of the data collection tools were mined by the researcher's research assistants, and were then compiled, coded and prepared for data entry. The data preparation process involved checking each entry for completeness before the data was logged. The data checking process therefore comprised a prior checking of the data for accuracy before it was entered into the Epi Info and the SPSS software.

3.4.1 The development of the audit tool

The researcher developed the data collection tool on the basis of a literature search and made recommendations about the measurement and monitoring of mortality trends. Information required for this purpose included the number of deaths in terms of age, gender, cause (whether direct, indirect, and the associated causes of death), date, and extent of residence aboard (see section 2.10). Because of the requirement of monitoring mortality trends in relation to the patient's free access to ART, other features that were included in the data collection tools were the patient's HIV status and the patient's history of ART participation. The researcher therefore developed audit data collection tools that will enable him to obtain the required information that is necessary for data analysis and subsequent discussion of results in relation to the study variables. This would enable him to comply with the requirements for quantitative data analysis and for the research in general. The data collection tools that were developed in this way ensured uniformity and consistency in the process of data collection. All of the data

connected with each individual death was compiled into the data collection tool by the trained research assistants.

Since the research instrument was designed to be completely unambiguous and unvarying in terms of the kind of data that it required, the data that was collected from the patient's records was simple and straightforward in terms of its parameters. Bowling (2007:258) refers to the ability of a structured tool to collect unambiguous and easy-to-count responses that would enable a clearly defined quantitative data analysis, as the advantage of such a tool.

The variables included in the data collection tool were selected in order to ensure that data could be extracted from the patient's case notes or records and that such data would be what was required for the research objectives. The relevant cases were identified from the hospital admission and mortality registers and records before individual case files were collected from the records department and were compiled into the data collection instrument. The data collection tool A was a simple data collection tool that consisted of a two page straightforward and unambiguous structured items. These two data collection tools were evaluated for internal, content and face validity by colleagues of the researcher and by the research supervisor.

The researcher therefore developed the data collection tool on the basis of the research questions and objectives of the study and on the kind of data that could be retrieved from the hospital's records. This tool guided the data collection process.

3.4.2 The structure of the data collection tool

The researcher used audit tools A and B to collect data from the hospital's records of the admissions and deaths that occurred in the hospital during the study period. The data collection tools focused on the specific variables that were necessary for accomplishing the study research questions and objectives. All the data collection elements were selected on the basis of their relevance to the study and were compiled in simple and easily comprehensible English. The data collection tool was deliberately structured in order to enhance the comparability of the information that would be collected from the records and in order minimize ambiguity. The audit tools consisted of sections that recorded the following information (see section 1.8.2.2), Audit tool A:

- Section 1: The patient's demographic profile
- Section 2: The last recorded visit that the patient paid to the hospital, and the Out-of-pocket payments that the patient made to the hospital
- Section 3: Whatever information was available from the patient's record about the patient's HIV status and access to ART
- Section 4: An endorsement by the research assistant

Data collection tool B was also specifically designed by the researcher for this study. The audit tool 2 (referred to as tool B) consisted of two sections that recorded the following information (see section 1.8.2.2):

- Section 1: The name of the hospital, the district and the date of data collection
- Section 2: A month-by-month summary of the number of adult admissions, the number of patients who are being treated by means of ART, and the total number of deaths
- Section 3: Information from the records about the supply of medicines and drugs

3.4.3 Rationale for using a structured audit tool

According to Hamer and Collinson (2005:129), a mortality audit is one of the numerous medical audits that serve the vital function of evaluating and confirming clinically effective care provided in health settings. It can also be immensely useful for guiding reviews to a variety of approaches to the delivery of health care. An audit tool retrospectively measures how well the clinical guidelines and standards that have been set for clinical care have complied with. The audit in this study was designed to determine whether a key objective of providing a specific service (which was, in this case, free access to ART in order to reduce the incidence of morbidity and mortality among patients) had been met or why it had not been met, and the suggestions for possible solutions to solve the problems that were identified.

Patient's records such as patient ward and outpatient registers, clinical notes and death certificates, all constitute a valuable source of information that can be used to answer specific research questions and provide possible explanations as to why a specific observation has occurred (LoBiondo – Wood & Haber 2006:328). Hospital records are a

cost-effective source of information (Brink et al. 2006:154). These records permit researchers to examine trends over time and to minimize or eliminate the need for a researcher to actively solicit the cooperation of participants.

The researcher used an audit tool to examine trends in adult mortality in the hospital and to identify the factors that contributed to the rates of adult mortality in the rural hospital setting by assessing the clinical care records of all the deaths that occurred in the hospital.

This method of data collection was a cost-effective for the researcher because the records were accessible and no consent or cooperation was required from the respondents. With a structured audit tool, the data that is collected is objective and consistent with the minimal bias that might arise between the two research assistants who had compiled the data from the available medical and hospital records.

3.4.4 Pre-testing the audit tool

De Vos et al. (2005:171-172) assert that newly constructed research tools should be thoroughly pre-tested before being utilised in an investigation. After the development of the audit tools, the researcher and his assistants pre-tested the research tools in the same hospital by sampling ten randomly selected mortality records from outside the study period and compiled the data using data collection tool A. Because the pre-test records were not identified from the study period, they were not included in the data that was compiled for the final analysis of this study. Tool B was pre-tested by reviewing the available hospital registers in order to determine whether the specified items could be compiled from the records. The data collected during the pre-test was then analysed to ensure that the data that had been collected from the medical records had adequately met the research objectives.

After the necessary (minor) changes had been made to the data collection tools, these tools were deemed suitable for data collection, and they were subsequently used for the purpose of data collection. This pre-test data analysis also ensured that the data collected would accurately measure the true attributes that would be able to provide answers to the study questions. Pre-testing or piloting ensures that errors are

immediately rectified in a cost-effective way before the implementation of the study is launched.

3.5 DATA COLLECTION

Burns and Grove (2001:49) *define data* collection as “the precise systematic gathering of information relevant to specific research objectives or questions.” “According to Burns and Grove (2001:50), data [can be] collected in several ways (depending on the study), and [can] include a variety of methods”. They point out, however, that the research objectives must be accomplished by means of the instrument that is used.

Data collection can be defined as the process of identifying or selecting subjects and gathering data from these selected individuals or subjects. The actual steps involved in the collection of data are specific to each study, and are derived from the research design and the methods of measurement that are used. Data may be collected by observing, testing, measuring, questioning, data mining (as in this study) or recording – or by any combination of any of these methods. The researcher should always be actively involved in this process, either by the collection of data, or in his or her capacity as the supervisor of the data collectors (Burns & Grove 2005:430).

The data for this study was gathered retrospectively by means of an audit tool that the researcher developed to accomplish his research aims and objectives. The data was collected from the records department of the hospital, where all patient files were kept under lock and key. To ensure and maintain the confidentiality associated with information contained in the records, it was not possible to remove any of the records from the records department. All the records associated with patients past and present therefore had to be examined in situ by research assistants. Even though the hospital authorities gave the researcher and his assistants their express permission to access and examine all records for the purpose of this research, the entire process of data abstraction was overseen and monitored by the hospital records clerk.

A structured audit tool used was constructed in such a way that all data would be presented in the same way. They were thus no variations in the wordings of each of the questions and categories, and some of these were associated with pre-coded response choices. After the researcher had trained and briefed all the research assistants, and

engaged them in the pilot phase, he was satisfied that each item in the data collection tools meant exactly the same thing to each of the data collectors (Bowling & Ebrahim 2005:394). Structured data collection tools of this kind have the capacity to collect and assemble unambiguous and easy-to-count answers, and such data is ideal for the purposes of quantitative data analysis.

The structured data collection tool that the researcher used for this study was in form of an audit tool that he developed on the basis of information and prototypes that he had examined in the literature review of the study. The data collection tool was therefore completely suited to accomplish the objectives of the study.

One may therefore assert that the data collection tool that was used complied with the following three requirements:

- It was **objective**. The data were not influenced by perspectives of the research assistant who collected the information
- It was **systematic**. The data was collected in exactly the same manner by everyone who was involved in the collection of the data.
- It was **consistent**. The data that was collected from each file in the study was collected in exactly the same way (or as close as possible to the same way). This served to minimise the bias that can be introduced into data collection methods when more than one person is embarking the collection of data (LoBiondo-Wood & Haber 2006:317-320).

Because the audit tools were objective and systematic, the data was collected in exactly the same way by the research assistants, all of whom had been trained by the researcher in the correct methods of data collection before they began to collect data from the hospital's records (Lobiondo-Wood & Haber 2006: 317-320). In this study, the data was collected by the research assistants who used the audit tool that had been custom-designed by the researcher to elicit the precise and exact responses that were necessary to answer the predetermined research questions. The development of this audit tool required decisions about the type of questions that needed to be asked, how the answers would be compiled, and, finally, a refinement of the audit tool so that there would be no redundant or unnecessary items. The following section explains how the researcher ensured that the research instrument would be objective and systematic.

3.5.1 The data collection process

The researcher requested an authorisation to collect data from the Research and Ethics Committee at University of South Africa (UNISA) (Department of Health Studies), The District Health Office and the management of the hospital in Mpigi district (see Annexure 3, Annexure 4 and Annexure 5).

The researcher was able to find two experienced research assistants to help with the collection of the data. He then trained these research assistants in how to collect the necessary information from all the available mortality records (which included the hospital's registers, the patients' death certificates and the patient case notes). The research assistants were also trained in how to compile the data they collected into the format of the data collection tools and to comply with the instructions that governed the process. The researcher himself validated the quality of all the data that was collected and supervised the research assistants throughout the data collection process. The researcher also checked the data that had been collected at the end of each week and identified any omissions or inconsistencies that would require the research assistants to check the records again and complete the data collection tools according to the requirements of the process. The data was collected over a period of six weeks between December 2008 and January 2009.

All data was collected from the hospital records section, where all the files of past patients were securely stored under lock and key. In order to ensure confidentiality, permission was never granted for these records to be removed from their places in the records section. Permission was, however, granted to the researcher and his assistants to access the records for the purposes of this research, and this process was supervised by the hospital clerk responsible for the records section.

After the cleaning and verification of the case summaries compiled into the audit tools format, the researcher entered the data into a pre-designed Epi Info database (version 3.5.1) designed by the researcher assisted by a colleague with advanced statistical analysis skills. During this last stage of data entry, further clarification was sought from the hospital records department for any missing or incomplete information, and when found it was added to the data base. In a number of instances, specific items were not available in the various records that were being used to compile the information, and

these patient histories were therefore relegated to the missing records pile on each analysis table.

3.6 DATA ANALYSIS

Data analysis consists of the systematic organisation and synthesis of research data and, in quantitative studies, the testing of the original hypotheses by means of such data (Polit & Beck 2008:751). The data analysis involved three major steps, namely, cleaning and organising, describing the data, and investigating the data for possible associations (Trochim 2006g:[1]).

In descriptive statistics a researcher organizes data in ways that will give meaning and explanation to various phenomena that seem to be unrelated and to explore a variety of phenomena from a number of different angles. Descriptive statistics include frequency distributions, measures of central tendency or dispersion and standardised scores (Burns & Grove 2005:461). In addition to this, Olds, London, Ladewig and Davidson (2004:17) state that descriptive statistics report the facts in a concise and easily retrieval way.

The researcher used descriptive statistics to describe and summarise data. Data was converted, condensed and categorised, into visual representations so that it would be more easily comprehensible to the average reader. The researcher used descriptive statistics mainly for the purpose of obtaining answers to his research questions.

Because this is a descriptive study, the researcher used descriptive statistics to describe the basic features of the data in the study. Simple summaries of information about the sample and various measures, together with simple graphic analyses, provided the basis of the quantitative analysis of the data in this study. In this study, the findings were presented and described in a manageable and easily understood format so that the key patterns or findings that emerged from the data would be readily observable (Rudestam & Newton 2007:27; Trochim 2006h:[1]). Descriptive statistics helped the researcher to reduce a large body of data to a series of plausible and comprehensible statements. Each descriptive statistic reduced the data into a simple summary that described a number of discrete events that initially might have seemed unrelated to one another. Wherever a number of observations are reduced to a single

indicator, there is always a risk of distorting the original data and losing important and telling details. However, despite these limitations, the use of descriptive statistics enabled the researcher to assemble a convincing summary that enabled him to make vital comparisons across variables (Trochim 2006h:[1]).

The research also performed bivariate analysis, and converted categorical variables with three or more levels or categories into two by two dummy variables. He then presented the results in terms of prevalence proportion ratios (PPR). All factors with significant odds ratio ($p < 0.05$) in the bivariate analysis were included in discussion. Chi-square statistics were also performed on those variables that revealed a high statistically significant association with hospital mortality.

The rest of the trend data was compiled and presented in terms of trends that occurred over time or in the form of time series in line graphs. Trend studies are recommended for the assessment of changes over time and for situations that are associated with *prediction* questions – mainly because, with such a technique, variables are measured at more than one time (Social Research Methods ca 2006:[2]; Van Aardt 2005:486). This study was designed to determine change in mortality trends in a rural hospital setting so that they would be useful to those responsible for macro policy and for decision makers who needed to make evidence-based decisions. In a trend analysis, data is collected at more than one point in time. This gives the researcher the opportunity of observing changes over time (Social Research Methods ca 2006a:[2]; Van Aardt 2005:486). In analyzing the data, the researcher drew conclusions and attempted to find correlations between variables. Both the advantages and disadvantages of trend studies are described below.

Disadvantages of trend studies: One of the limitations of trend analyses arises out of the fact that they are subject to threats of validity. Thus, for example, when data is unreliable, a researcher may end up with false or invalid trends. Trend studies may also reveal pseudo-trends. These are caused by changes in methods of measurement – and can deceive both researchers and readers alike (Social Research Methods ca 2006a:[2].) In this study, the approach and formats of recording deaths in the hospital did to undergo specific changes that could lead to changes in methods of measurement of a recorded event. Therefore, in the study period, the recording of a death was similar in terms of the key variables included in this analysis and was thus comparable across

the years. The risk of changes in methods of measurement was thus not a factor and a not a risk to this study.

Advantages of trend studies: The main advantage of trend studies is in their ability to describe long-term changes in a population. They can also establish a pattern over time that will enable a researcher to identify changes in a series of event (Social Research Methods ca 2006a:[2]).

The study was undertaken to evaluate the trends and patterns of mortality through the compilation of mortality data in terms of the causes of patient mortality, as well as the gender and age (and other information about the patient) with regard to all adult deaths that occurred in the hospital setting. This data analysis was performed for both the pre-free and post-free ART eras. The researcher then compared the trends from the two periods and drew various conclusions from the analyses thus compiled. These comparisons enabled the researcher to present and develop a discussion and make possible recommendations for government policy makers and programme designers.

3.7 VALIDITY AND RELIABILITY

The following section explains the concepts of validity and reliability as applied to this research.

3.7.1 Validity

Validity is defined by Polit and Beck (2008:457) “as the degree to which an instrument measures what it is supposed to measure”. Rudestam and Newton (2007:113) define *internal validity* as “the degree to which the results of an observation are correct for the particular people” (or sample) which is being studied. *Validation* is the degree to which the trustworthiness of the reported study observations, interpretations and conclusions can be assured (Rudestam & Newton 2007:113). Validity is therefore the extent to which a measure “in fact measures what is purports to measure” (Rudestam & Newton 2007:96).

In simple terms, “validity refers to whether or not the measurement collects the data required to answer the research question” (Somekh & Lewin 2006:216).

Validity is categorised into the following three forms. *Content validity* is extent to which the items in the study tools measure the content or variables that they were intended to measure. *Predictive or concurrent validity* is the extent to which it is possible that the scores in the survey tool effectively do, in fact, predict a criterion measure and whether the results thus obtained correlate with other measures. *Construct validity* is the degree to which the scores that are obtained serve a useful purpose and will result in good outcomes and positive consequences when they are used (Creswell 2003:157-8.)

The focus of this study was to determine changes in mortality patterns and also to determine the association between changes in mortality patterns and free access to ART as an intervention. Basically, what the researcher wanted to know was whether there was any significant relationship between the introduction of free access to ART in the rural hospital and the prevailing mortality trends post-free ART eras. He also wanted know whether there was any corroborating evidence for the truth of possible associations that had been reported in other studies (Trochim 2006i:[1]).

Rudestam and Newton (2007:113) define external validity as the “generalisability of the findings of the study”. *Generalisability* refers to the extent to which the results of a study can be validly applied to the wider population that the group represents or a highly similar group in other contexts (Somekh & Lewin 2006:216). Generalisability in this study is limited to the mortality trends in all similar rural hospitals across Uganda at the same time as the period during which the study was being conducted. But such similarities are nevertheless indicative of what may have happened (or be happening) in the similar settings.

In this study, the researcher emphasised specific aspects of validity and their applications, and these are all described below.

3.7.1.1 External validity

“*External validity* refers to the generalisability of the research findings to the wider population of interest”(Beaglehole et al. 2000:50; Bowling & Ebrahim 2005:398). The researcher achieved external validity by using a statistically significant sample of the population available for his particular study in order to increase the generalisability of his research findings.

3.7.1.2 Internal validity

Internal validity is defined as the degree to which the findings or results of an observation reflect an accurate description of what is happening in the sample population that is being studied (Beaglehole et al. 2000:50). A tool or instrument is said to possess internal validity if it has produced satisfactory results after having been repeatedly tested in the population for which it was designed (Bowling & Ebrahim 2005:398).

The researcher pre-tested the audit tool in this study to ensure that it measured what it was supposed to measure, that is, the trends and other elements of interest that contributed to adult mortality in a rural setting in Uganda.

3.7.1.3 Content validity

The *content validity* of a data collection tool refers to the degree to which the items in the data collection tool adequately represent the phenomenon that has been selected for study (Parahoo 2006:304).

The researcher used content validity to measure the degree to which the audit tool measured the range of meanings that are inherent in the concept by conducting a logical analysis of the kind described by described by Babbie and Mouton (2007:123). Burns and Grove (2005:377) describe the content-related validity of a data collection tool “as the extent to which the method of measurement includes *all* [the] major elements” that are descriptors of the concepts that a researcher wishes to measure and describe.

The audit tool was validated by means of a technical review conducted by health experts in the field of public health research and health care professionals who were responsible for providing health care in health facilities that were located in similar rural settings as the hospital in the study. Among these experts were the District Health Officer, the medical officers who worked in the hospital, and other health professionals who were experienced in the field of public health research. All of their suggestions were considered by the researcher and included in the final version of the audit tool

before he used it for the collection of data. He also viewed his literature review in order to ensure that all the relevant items were included in the audit tool.

3.7.1.4 Face validity

“*Face validity* refers to [an] investigator’s subjective assessment of the presentation and relevance of the” (Bowling & Ebrahim 2005:398) questionnaires. Such an assessment requires him to certify that all the data collection items in the audit tools appear to him be relevant, reasonable, unambiguous and clear – in accordance with the procedure suggested by Bowling and Ebrahim (2005:398).

The researcher therefore requested various experts in public health research and health service delivery in similar settings, who possessed the necessary research experience, to assess the audit tool for practicability, ease of use, and its ability to collect the necessary data that he required in order to answer the research questions that formed the basis of this study. After considering their suggestions, he incorporated them into the final versions of the audit tools that he used for the data collection process.

In this study, internal validity was enhanced by making use of structured audit tools, by a careful prior training of data collection assistants, and by the meticulous attention to detail. Internal validity was also be enhanced by random verifications of the completed data collection tools by the principal researcher. The sample size was adequate because it consisted of an estimated 4.7% of all the deaths that had occurred in the district and 20 % of all the deaths that occurred in the health facilities in Mpigi (see section 3.3.4). The researcher’s data collection tools were also approved by the study supervisors and the researcher was able to give the assurance that all of the data collection items that were required for answering the questions were included in the collection tools. The researcher then proceeded to pre-test the data collection tools.

3.7.2 Reliability

De Vos et al. (2005:162 -163) define *reliability* as the stability or consistency of the measurement process over time. Reliability can also be defined as the repeatability of measures or the ability of a research instrument to measure and produce consistent results in similar circumstances and environments (Beaglehole et al. 2000:49;

Rudestam & Newton 2007:96). If the same variable is measured under similar conditions, a measure or procedure that is considered to be reliable would produce similar results. Reliability is therefore the ability of a tool to produce consistent numerical results each time that it is applied (Rudestam & Newton 2007:113; Somekh & Lewin 2005:216). “Reliability is [also] concerned with the consistency of the measurement [techniques]” (Burns & Grove 2005:374). Reliability is therefore a measurement of the extent of the precision and accuracy of the data collection instrument.

The reliability of the audit tools was evaluated by pre-testing and the revision of the data collection tools before they were used for the study. Pre-testing ensured that the tools would be capable of producing consistent results under similar conditions.

In this study, the data collection items were carefully phrased in order to avoid ambiguity. The reliability of a research instrument is also related to the characteristics of the population that the instrument is designed to measure (Rudestam & Newton 2007:96). A measure may be unreliable because it may be difficult for the subject to understand the question (as in the case, for example, of ambiguous questions) or because the setting or methods of administration affect the stability of the measuring instruments (Ovretveit 1998:214).

In this study, the ambiguity of the data collection tool was maximised by the use of structured audit data collection tools that enhanced the extent of reliability. Reliability was also enhanced by a data collection tool that was developed on the basis of the researcher’s research objectives and by a process of pre-testing that would ensure that the tool was able to measure the key variables of the study. Reliability was also enhanced by a data collection approach that systematically standardized the retrieval of all the information from all the (usable) records of all reported deaths. This data collection approach was highly reliable, and it will be able to obtain the same outcomes if the study is repeated. The results of this study can therefore be replicated by a researcher who uses the same approach, research design, research instruments and a setting that is almost identical to the original research setting in the rural hospital.

The training of the research assistants so that they clearly understood the purpose the study, the methods that would be used in data collection, and the ethical principles that governed the research process, also contributed to the overall reliability of the data

collection process. Clearly defined parameters in the data collection instrument and the use of two research assistants minimized the risk of inter-observer differences and thus enhanced the accuracy of data that was collected. The researcher also enhanced the reliability of the data that was collected by soliciting peer review of the input and the results in order to test the data collection tool for relevance and coherence of structure.

Since both validity and reliability are vital considerations for undertaking a study, it is important to note that a measure might be reliable (i.e. it will always generate the same results) even though it might not be valid (i.e. it does not measure the concept that it was intended to measure) (Somekh & Lewin 2005:216).

3.8 ETHICAL CONSIDERATIONS

Ethics may be defined as “moral principles that control or influence a person’s behaviour, or a system of moral principles or rules of behaviour” (Hornby 2005:498). All researchers are responsible for conducting their research according to the ethical principles recommended by the institution to which they are presenting their study and ethical principles that are universally accepted in the worldwide research community as essential for the achievement of morally acceptable research results. Any failure or breach of such ethical principles would bring the scientific process into disrepute and negate the acceptability of the research results (Brink et al. 2006:30). The three fundamental ethical principles that guide all research work include: *respect for all the people involved in the research, beneficence and justice* (Brink et al. 2006:31).

These principles are based on the declaration of human rights that was explicitly promulgated in the Universal Declaration of Human Rights that was accepted by the General Assembly of the United Nations on 10 December 1948, and which has been accepted and observed by all civilised nations who are signatories to the declaration. These universal principles of human rights are the basis for the human rights that are protected in the processes of scientific research. They include the right to privacy, the maintenance of anonymity and confidentiality, the right to fair treatment and protection from from any kind of discomfort and harm (Brink et al. 2006:31). The ethical conduct of public health search not only focuses on the participants of the study, but also on other people or communities whose health needs to be protected or improved by the application of the research findings (Beaglehole et al. 2000:50)

In order to accomplish this study in an ethical manner, the researcher obtained permission from the Ethics Committee of the University of South Africa, authorization from Mpigi District Administration, and similar authorisation from the hospital management (see Annexure 3, Annexure 4 and Annexure 5). All the information that was obtained as a result of the study was used solely for the purposes of this study alone, and any publication in scientific journals needs to be subject to the prior approval of Mpigi District Health Office. The study focused on the medical records of dead patients and the principle of respect for the deceased patients and their personal information was closely adhered to. With regard to the principle of beneficence, the researcher ensured that this study would benefit the institutions that were involved in the study in the planning and development of their interventions to minimize mortality. The researcher also took measures to ensure that during the implementation of the study, no participant would suffer any kind of extraneous discomfort or harm – whether physical, emotional, spiritual, economic, social or legal (Brink et al. 2006:32). Justice was ensured by the application of a fair and a transparent approach to the selection of the subjects who participated in the study, and each case record was treated with the utmost privacy and confidentiality.

The principle of voluntary participation (Beaglehole et al. 2000:50) and the protection of the participants from harm were achieved by means of obtaining the approval of the district and hospital management boards. This ensured that the study was in compliance with research guidelines and was sound enough to ensure the protection of participants. The District Health Officer and the hospital management were provided with comprehensive summaries of the information that was relevant to their participation in the study in both written and verbal forms. This procedure helped them to become aware of the benefits that might result from the study. All the information that was collected was treated with confidentiality and was not made available to any unauthorised individuals who were not directly involved in the study. The researcher adhered to the principles of *voluntary participation*, *confidentiality*, *informed consent* and *the minimisation of harm* in this study.

The medical research establishment has promulgated various ethical measures to protect the rights of volunteers who participate in research projects. These ethical standards also require that researchers not to place any participants in situations in which they might be at risk of harm as a result of their agreement to participate (Trochim 2006j:[1]). The risk of harm in this study were indeed minimal because none of the

procedures in this study involved any kind of invasive procedures, but consisted almost wholly of a review of the personal hospital medical records of deceased patients who had already died in the hospital prior to the commencement of the study. The researcher explained the scope and benefits of the study to the district and hospital management and he obtained the informed consent of the guardians of the patient records of the hospital before he commenced the study.

The hospital records were carefully respected and handled, and were all returned to their exact locations once the research assistants had obtained the data that they required from each of them. No patient file was ever removed from the hospital records department. *Anonymity* means that no one – not even the researcher himself – knows the identity of the participants whose personal details and information were used in the study (Rudestam & Newton 2007:280). After transcribing the information from the records, the researcher made use of a *hospital reference number* for validating the information that had been collected in each case, and in order to undertake any further clarification or validation of the information that might have been needed.

After the data had been transcribed by the data collection assistant, the case files were triangulated with other records such as the death certificates and ward registers. This process was accomplished by making use of the hospital reference numbers mentioned above. The researcher trained the data collection assistants to maintain the confidentiality of patient records, and *only* the required information that was necessary for completing the data collection tool was extracted from the hospital patient records. All data collection forms were subsequently endorsed by the research assistant, and the researcher himself performed random validations of the information that the research assistants were transcribing from the records. Two other aspects of the ethical principles that govern research are described below.

Ethical considerations during data analysis: In the analysis and interpretation of findings, issues emerge that necessitate sound ethical decisions (Creswell 2003:66). The anonymity of individuals was maintained in the data collection process. The data collection instruments will be kept for three years after the study has been presented before they will be finally disposed of.

Ethical considerations in the dissemination of the findings: In the writing the report, the researcher exercised caution in order to ensure that no use of language and words that could create bias or prejudice against particular people because of gender, race or ethnicity, disability or age (Creswell 2003:67; Rudestam & Newton 2007:282). In spite of this, the researcher did not intentionally suppress, falsify or invent any findings to bias the terms of the research towards his own implicit expectations or those of the audience or possible readership (Creswell 2003:67; Glatthorn & Joyner 2005:12). In other words, the researcher explicitly declares that he did not engage in any fraudulent practices in any part or process of this study. The researcher was also committed to ensuring that the results of this study would not be interpreted in any manner that would provide support for the prejudices and biases of any particular interest group or lobby.

3.9 THE LIMITATIONS OF THE STUDY

Firstly, the limitations of the study were mainly connected to the incomplete state of the hospital's patient records. The inadequate focus on mortality data over a period of time resulted in inconsistencies in the records to an extent that made the process of data collection vulnerable to data collection researcher biases – especially in those cases in which the diagnoses were not well written out or were incomplete or incoherent in the records. Although the researcher made attempts to ensure that the audit tools were as complete as possible and in although he utilised the technique of triangulating the hospital's records to ensure that the information collected by the data collection tool would be as accurate as possible, this deficiency remains an inherent limitation.

Secondly, this study did not focus only on the mortality trends among patients on ART but on the overall mortality trends in the hospital. While the effects of ART are most appreciated by patients who are actually receiving ART, a more detailed focus on ART patients, the length of time during which they had been on ART, the key outcomes of the ART access programmes, and the specific qualitative interviews of patients on ART and health workers were beyond the scope of this study.

Thirdly, the diagnoses that were used in this analysis were based on clinical diagnoses, on limited laboratory investigations and on post-mortem diagnoses of the cause of death. These diagnoses were therefore not confirmed, but were classified in terms of

good clinical practice, and, to a significant extent, they portrayed the patterns of illnesses that occurred in this rural setting during the period of this study.

The efforts of the researcher to minimise errors and misinformation by the careful training of research assistants and the utilisation of an audit tool, went a long way in guiding the data collection processes and in minimising bias. Despite these limitations, the findings of this study are vitally important because they can function as a benchmark for mortality audits in other hospitals in Uganda, and will therefore be able to serve as a basis for sound evidence-based decision making.

3.10 CONCLUSION

Chapter 3 covered the research design and methodology, and described the study population, the sampling approach, the sample itself, the research instruments, the process of data collection, the way in which the data was analysed, the ethical principles that governed the conduct of the study, and the limitations of the study.

Chapter 4 sets out the data analysis and the interpretations of the findings of the study.

CHAPTER 4

Presentation and interpretation of findings

4.1 INTRODUCTION

The previous chapters of this study dealt with the background, literature review, the research design and methodology of this study. This chapter focuses on the data analysis, the findings and the interpretation of the results of the study. The data analysis involved data cleaning, the organisation of the data for analysis, the data analysis itself, a description of the data and an interpretation of the findings (Trochim 2006j:[1]). From the introduction and the background that was he presented in chapter 1, the researcher formulated the following research question: *What have the overall adult mortality trends been in the rural hospital setting chosen for this research since the introduction of free ART in Uganda?* This study has therefore focused on the determination of mortality trends, an identification of the factors associated with death and the causes of adult mortality in the rural hospital setting that was chosen for the study. The study also compared the overall hospital mortality trends in the post-free ART period with the overall hospital mortality trends that prevailed in the pre-ART era.

The overall purpose of this study was therefore to identify and analyse the mortality trends and demographic characteristics of those patients who died in a rural hospital in the Mpigi district of Uganda over a period of six years. The study reviewed the trend of mortality in terms of causes and the percentage of deaths that were caused by HIV/AIDS-related illnesses before and after the roll out of free ART to HIV-infected patients. The focus of this study was on Mawokota South County, which is also referred to as the Mawokota South health sub-district. This county is one of the four counties that form the Mpigi District of Uganda. The other three counties of the district are Maddu, Butambala and Mawokota North. Since the government of Uganda through the National Health Policy has empowered each health sub-district with the responsibility of ensuring the health of the whole population in any particular county, the county is therefore the catchment population of each health sub-district (Ministry of Health – Government of Uganda 2005:20).

Mawokota South health sub-district is responsible for a catchment population of 99 607 (Lumala 2008:10) in three sub-counties, namely Buwama, Nkozi and Kituntu. The hospital located in Mawokota South health sub-district is the headquarters of the health sub-district and was chosen by the researcher as the focus of this study. The hospital that forms the basis for this study is a district level general hospital and a private-not-for-profit hospital that is responsible for the provision of preventive, curative and rehabilitative care and referral services. It also functions as the base and headquarters for the health sub-district management team. In Uganda, 29 (13.6%, n=214) of the health sub-district headquarters are private-not-for-profit hospitals (Ministry of Health – Government of Uganda 2005:20). The hospital that the researcher chose for the study therefore offers a wealth of experience in the long history of health care provisions that are similar in most ways to other settings throughout the country. It therefore provided the researcher with an ideal opportunity for reviewing and developing interventions that would serve to reduce the rates of hospital mortality throughout Uganda as a whole.

The objectives of this research study were:

- To investigate the trends exhibited by adult hospital mortality rates and to compare the trends of the pre-free ART period to the trends of the post-free ART periods in the rural hospital in the Mpigi district of Uganda.
- To determine the overall effect of free ART access on hospital mortality rates in the rural hospital in the Mpigi district of Uganda.
- To make recommendations about ways in which the provision of free ARVs could be administered so that the exceptionally high mortality rates in the Mpigi district and in similar settings in Uganda could be radically reduced.

The Uganda National Strategic Plan for HIV/AIDS was developed as a direct response to the AIDS epidemic, and covers the period from between July 2007 and June 2012. This plan provides hospitals, physicians and health care administrators with the direction they need to plan and implement interventions that will reduce the incidence of HIV-related morbidity and mortality. The plan is designed “achieve universal access targets for HIV & AIDS prevention, care, treatment and social support by 2012” (Ministry of Health – Government of Uganda 2009:21). Among the objectives of this plan are the following:

- to improve the quality of life for PLWHA
- to mitigate the social, cultural and economic effects of HIV & AIDS at the levels of individuals, households and communities
- to design, construct and sustain effective support systems that will ensure the quality of access as well as equitable and timely patterns of service delivery

This plan is based on the “need to generate evidence about the effectiveness, efficiency and relevance of the national HIV & AIDS response interventions so that they can be continuously improved” (Ministry of Health – Government of Uganda 2009:21.)

Although the results of this study cannot be generalised to morbidity and mortality patterns in all other rural hospital settings in Uganda, it has identified key mortality factors and trends in Mpigi District in both the pre-ART and post-ART eras. The findings of this study therefore provide powerful benchmarks for assessing the effectiveness of free access to ART in typical rural communities in countries such as Uganda.

Chapter 4 presents the methods of data collection that the researcher used, the data analysis itself, the findings of the study, and a concluding discussion on the significance of the data and what one can deduce from the way in which the data was analysed.

4.2 DATA COLLECTION

The researcher collected the data by using structured audit tools A and B. He compiled the data from available hospital admission and death records which included patients’ case notes, ward registers and death certificates. Audit tool A consisted of the following sections (these are also described in section 1.8.2.2):

Section 1: The demographic profiles of patients

Section 2: Information about the last visit that a patient made to the hospital. This included information about the date of admission, the date of death, the reason for admission, the cause of death, and the out-of-pocket payments that the patient made to the hospital for the health services that he or she received.

Section 3: This section assembled information from the patient's records that related to HIV infection – information that included the patient's HIV status (if recorded), the patient's history of being on an ART regimen, and the date when the patient began to receive ART for the first time.

Section 4: The last section consisted of an endorsement by the research assistant.

Audit tool B consisted of the following three sections (also referred to in section 1.8.2.2):

Section 1: The name of the hospital, the district in which it was situated, the date on which the data was collected.

Section 2: A month-by-month summary of the number of adult admissions, the number of adult patients that were receiving ART, and the total number of all deaths.

Section 3: This section described the ART medicines/drugs that were (in terms of the records available in the hospital) available to HIV/AIDS patients.

4.3 DATA ANALYSIS

This study reviewed 561 death records of which 17 death records were so incomplete and were thus excluded in this analysis. Therefore, 544 deaths that occurred over a period of six years in a rural hospital in Mawokota South health sub-district in the Mpigi district of Uganda were analysed. All this data was entered into the Epi Info (version 3.5.1) and the SPSS (version 12.0) databases and analysed by the researcher with assistance from a colleague proficient in statistical analysis. Graphical presentations of the results were subsequently constructed by utilising the Microsoft Office Excel Worksheet (xlsx) program and the SPSS program.

The parameters that were analysed related to the overall mortality trends included the age, gender, hospital length of stay and the out-of-pocket payments that patients made. Descriptive statistics were used to describe the basic features that were discernible in the data and to transform them into summaries that formed the basis for the subsequent discussions. Graphic presentations were then developed from a quantitative analysis of

the data so that the various findings could be more easily visualised (Trochim 2006k:[1]). The use of descriptive statistics enabled the researcher to simplify the data into a simple, straightforward and easy flow of ideas. Each descriptive statistic reduced the data into a form of a simple summary that illuminated a number of otherwise discrete and apparently unrelated events.

Bivariate analysis refers to the analysis of the relationship between two variables (Tustin 2005:646). The researcher therefore carried out bivariate analyses and – by making use of a specific rationale – he grouped together variables with three or more categories into two broader categories and then proceeded to analyse them. The results are presented in terms of prevalence proportion ratios (PPR). The researcher also conducted chi-square statistical procedures by using two by two contingency tables to determine the statistical significance of the association between specific factors and rates of hospital mortality. All factors with significant odds ratios and a p value < 0.05 in the bivariate analysis were included in discussion.

The remainder of the data trends were compiled and presented as trends that occurred over a period of time or by means of a time series that made use of line graphs. Trend studies are recommended for assessing changes over time and for situations that require or relate to prediction questions, mainly because variables are measured at more than one time (Social Research Methods ca 2006:[2]). The researcher accomplished the trend analyses by using data that had been collected on a monthly basis over a period of 72 months (six years) by the hospital authorities. This gave the researcher an opportunity to observe changes over a period of time, and enabled him to forecast three years of trends in the period that ended in June 2011 (Social Research Methods ca 2006a:[2]; Van Aardt 2005:484).

Because of the seasonal variations in hospital morbidity and mortality data, the researcher compiled and smoothed the time series by using the Exponential Smoothing (ES) technique. Exponential Smoothing is a forecasting method that is used for modifying a time series that exhibits seasonal variations (Arsham 1994:[21]). The concept of a time series considers each observation to consist of a constant in conjunction with an error component in each segment of the series, and although the constant is relatively stable, it can change over time.

The formula for exponential smoothing is:

$$F_{t+1} = \alpha D_t + (1 - \alpha) F_t$$

Where: D_t = the actual value; F_t = the forecasted value; α or a = the weighting factor, which ranges from 0 to 1; and t = the current time period.

The smoothed values are the forecast for period $t + 1$. In this study, $t + 1$ is the current month plus one, which is the forecast for the subsequent month (Arsham 1994:[21]). Each smoothed value was calculated as the weighted average (based on the dumping factor) of the current observation and the previous smoothed observation. Therefore, each smoothed value was based on the weighted average of the previous observations, which decrease exponentially, depending on the value of parameter α (alpha) (StatSoft Electronic Statistics Textbook: Time Series Analysis n.d.:[10].)

In the analysis of hospital mortality trends and three-year trend forecasts, due to the importance of increased ART coverage in determining morbidity and mortality trends, a dumping factor of 0.95 was applied. By application of the 0.95 dumping factor to mortality and morbidity data, the most recent observations were given more weight in determining future trends compared to previous observations. Individual observations declined exponentially, indicating the importance of key aspects of the most recent post-free ART era in terms of ART coverage on mortality trends in determining future trends when compared to earlier pre-free ART observations.

The researcher used the Exponential Smoothing (ES) technique in this analysis to adjust for past errors, to produce a wide variation of monthly statistics, and to prepare three-year forecasts. He then included both graphs (representing the actual data collected and the smoothed data) together on one chart, and summarized discussion about the observations below the graphs. By means of this analysis, the researcher developed predictable trends and forecasts that will serve as a guide for decision making in Mawokota health sub-district and in the Mpigi district in general.

The gender distribution (female:male) in Uganda is 51% females and 49% males (Uganda Bureau of Statistics, Government of Uganda 2006:viii). That the different effects of health conditions and the different responses of individuals to their disease

conditions depend on their gender, is a fact that cannot be sufficiently overemphasised. The gender composition of a population therefore has significant implications for developing targeted and effective interventions (Uganda Bureau of Statistics, Government of Uganda 2006:viii). Because of the crucial importance of this effect, mortality rates and all factors related to mortality were analysed in this report both in general (i.e. with male and female data combined), and according to gender. The reason for making gender-focused analyses was to determine the varying effects and trends of mortality in terms of the different effects produced by gender so that programme planners could design more accurate and specifically targeted interventions.

In the course of analyzing the data, the researcher also investigated the association between variables and drew possible conclusions, identified un-answered questions, and recognised where information gaps would appear for future research. This study was designed to determine the course of adult mortality rates over a six-year period in a rural hospital setting.

The results of this study were designed to guide decision makers in the making of evidence-based decisions and in the development of approaches for evaluating mortality trends in the pre-ART and post-ART eras so that they could implement targeted interventions to reduce rates of mortality and morbidity.

4.4 FINDINGS OF THE STUDY

The first item in the presentation of findings of the study begins with the demographic profile of the study population. After that, the researcher reviews morbidity and mortality trends and analyses the factors associated with mortality. The presentation then continues with an analysis of factors that are associated with mortality in the pre-free and post-free ART eras before concluding the chapter.

The researcher made assumptions at the beginning of the study. The accuracy of these assumptions was confirmed during data collection. Since the collection of data involved an audit that was conducted by means of sifting or mining data from existing hospital records, a pre-testing of the audit tool enabled the researcher to narrow down the

variables on the basis of on the information that he could compile from the hospital mortality records.

The first assumption that the researcher made was that all hospital-based deaths had been duly recorded and certified. Although it emerged that all deaths had indeed been recorded, not all duplicate death certificate records were available for analysis. In those cases where the copy of the death certificate was not available, the cause of the patient's death was compiled from the patient's ward registers or treatment records. The second assumption was that all hospital deaths had all been written up by qualified health workers who had recorded and investigated the primary and associated causes of death. But because of limitations on resources and the professional technical expertise required to carry out post-mortem analyses, the causes of death had not been confirmed by post-mortems. The direct or primary cause of death and the associated causes of death were in each case based on the clinical presentation of the patient at the time of death and the limited laboratory tests that had been available in the hospital for purposes of diagnosis. The third assumption that the research made was that the free uptake of ART in the hospital had not been interrupted ever since the patient had commenced with his or her ART regimen and that ART was freely accessible to the whole catchment population of the hospital. An analysis of the supplier of ART medications was not, however, included in the researcher's analysis.

The HIV status of individual patients, the history of their observance of the ART dosage regimen, and the dates on which individual patients began to participate in ART, were incomplete, and were therefore not taken into account for this analysis. The HIV status of patients was in fact inferred from the reported direct and associated cause/s of death.

The discussions about the conclusions that the researcher reached are based on the findings that were compiled and analysed in terms of references to the deaths (mortalities) that had occurred in the hospital from between July 2002 and June 2008. This analysis in this study was based on the findings of the Ugandan Government's financial and reporting year that run in cycles between 1st July and 30th June of the following year. The pre-free ART years that are referred to in this analysis include the years 2002/2003, 2003/2004, 2004/2005, and the post-free ART years include the years 2005/2006, 2006/2007, 2007/2008.

4.4.1 The demographic profile of the study population

This section describes the study population in terms of age, gender, sub-county of residence, year of death, and by the treatment era in which they were living when they died (either the pre-free and post-free ART era).

4.4.1.1 Age distribution of the study population

The ages of the patients at the time of their death were compiled from the hospital records. Every patient (or a relative of the patient) is routinely asked for age when he or she is admitted. The reported age was then recorded as the patient's age at the time of admission in the patient's admission notes and ward registers. Since most of the patients died shortly (within 0 [zero] and 67 days) after admission, the recorded age on admission was considered as the age at time of death.

Vital information registration systems in Uganda are generally of a poor quality. Despite the errors associated in hospital records with regard to the reported age of patients (misinformation that includes ignorance about the exact date of birth, the age of the patient upon admission, or even deliberate misreporting), the reported age in these records was the only recorded age-related information that was available to the researcher for this analysis (Uganda Bureau of Statistics, Government of Uganda 2007:15).

The errors that were previously associated with the recording of reported ages in Uganda have nevertheless shown a downward (reducing) trend over the years. One finds, for example, a more accurate reporting of ages in the 2002 census than one finds in the 1969 census (Uganda Bureau of Statistics, Government of Uganda – 2006:15). Since one may assume that the reported age in health facilities was within limits of the actual age of the patient, the reported age as recorded in the hospital records was used by the researcher for analysis in this study. In order to guide the analysis, the researcher grouped the ages into the following categories: 15-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84 and 85. He also recorded the gender of each patient for the purposes of statistical analysis, tests and comparison.

The researcher standardised and analysed the hospital mortality rate by comparing the Crude Death Rates (CDR). The Crude Death Rate is defined as the “number of deaths over a given period divided by the person-years lived by the population over that period. It is expressed as number of deaths per 1,000 population” (United Nations – Population Division of the Department of Economic and Social Affairs 2009a:[1]). By making use of the CDR, the researcher compared the annual hospital-based mortality rates by age group to the general population figures reported by the United Nations and the Uganda Demographic Health Survey of 2006. This analysis provided an overall summary of hospital mortality rates in this rural setting.

Table 4.1: Hospital mortality rates categorised by age and gender

Age group (years)	Female deaths <i>n</i> (%)	Male deaths <i>n</i> (%)	TOTAL number of deaths in 6 years <i>n</i> (%)	The Uganda National age-group distribution of the population* (%)	Estimated population of Mawokota South health sub-district by age-group	Age adjusted crude death rates by age group per 1 000 population
15-24	25(47.2) (13.2)	28(52.8) (9.0)	53 (10.6)	20.2	20164	0.4
25-34	57(45.2) (30.0)	69(54.8) (22.2)	126 (25.1)	13.2	13108	1.6
35-44	38(34.5) (20.0)	72(65.5) (23.2)	110 (22.0)	7.1	7094	2.6
45-54	17(29.8) (8.9)	40(70.2) (12.9)	57 (11.4)	4.4	4394	2.2
55-64	15(34.9) (7.9)	28(65.1) (9.0)	43 (8.6)	3.1	3110	2.3
65-74	15(26.8) (7.9)	41(73.2) (13.2)	56 (11.2)	1.8	1791	5.2
75-84	19(42.2) (10.0)	26(57.8) (8.4)	45 (9.0)	0.7	718	10.4
≥85	4(36.4) (2.1)	7(63.6) (2.3)	11 (2.2)	0.1	97	18.9
TOTAL	190(37.9)	311(62.1)	501	50.7	50475	9.9

(*n*=501, *missing* = 43),

(*Source: United Nations - Population Division of the Department of Economic and Social Affairs of the 2009b:[1-2])

The age distribution of 501 deaths was 15-24 (10.6%), 25-34 (25.1%), 35-44 (22.0%), 45-54 (11.4%), 55-64 (8.6%), 65-74 (11.2%), 75-84 (9.0%) and above 85 years (2.2%).

In the 15-64 age bracket (the economically active population), the highest CDR was in the 35-44 age group of 2.6 per 1 000. The CDR was lowest in the 15-24 age group (0.4 per 1 000 population), which also is reported to have the lowest prevalence of HIV (3.1%) in the 15 years and above age-group population in Uganda (Uganda AIDS

Commission – Government of Uganda 2006:21). The CDR in the 35-44 age group (2.6 per 1 000 population) was six times the CDR in the 15-24 age group and 1.6 times the CDR in the 25-34 (1.6 per 1 000 population) age group.

Comparatively, the Uganda demographic health survey showed that mortality in the 35-44 age group (with a CDR of 15.7 per 1 000 population) was four times the mortality in the 15-24 age group (at 3.8 per 1 000 population) and 1.6 times the CDR in the 25-34 age group (at 9.6 per 1 000 population) (Uganda Bureau of Statistics – Government of Uganda 2006a:280). The hospital-based CDR was therefore comparable to the adult mortality patterns in the general population.

The findings also showed that, in the 15-64 age bracket, the CDR peaked (was at its highest) in the 35-44 age group, and that CDR progressively decreased in the 45-54 age group (2.2 per 1 000 population) and the 55-64 age group (2.3 per 1 000 population). These findings coincided with the high HIV prevalence in the population which peaks in the 35-44 age group at 9.2% (9.6% for the 35-39 age group and 8.8% for the 40-44 age group) (Uganda AIDS Commission – Government of Uganda 2006:21).

After the age of 65, the CDR subsequently doubled for every ten year age group. In the 65-74 age group, the CDR was 5.2 per 1 000 of the population compared to 2.3 per 1 000 of the population in the 55-64 age group. In the 75-84 age group, the CDR was 10.4 per 1 000 of the population. When this CDR is compared to that of the 65-74 age group and that of the population above 85 years, the CDR stood at 18.9 per 1 000 population, which represented twice the CDR in the 75-84 age group. In all age groups, the hospital-based CDR was highest in the above 85 year age group.

The overall CDR was 9.9 per 1 000 population, which was comparable to the CDR of Uganda at 12.9 per 1 000 of the population in the general population and the CDR of 8.8 per 1 000 of the population in the 15-49 age group (Uganda Bureau of Statistics – Government of Uganda 2006a:280; United Nations – Population Division of the Department of Economic and Social Affairs. 2009c:[1]).

To summarise, the distribution of mortality in terms of age group showed that, proportionally, the highest number of deaths occurred in the 25-34 age group, which

accounted for 25.1% (n=501) of all adult hospital deaths. It is important to note that the CDR in the 15-64 age bracket was highest in the 35-44 age group (2.6 per 1 000 population), which coincided with the highest HIV-prevalence rate in the adult population. The findings also show that after the age of 65 years, hospital-based CDRs doubled for every successive ten-year age group. Overall, the age-standardised CDR was lowest in the 15-24 age group (0.4 per 1 000 population) and highest in the 85 year age group (18.9 per 1 000 population). The overall CDR was 9.9 per 1 000 population.

4.4.1.2 Mortality distribution in terms of age and gender

HIV/AIDS affects specific genders and age groups differently. In Uganda, females experience a higher prevalence of HIV-infection compared to males, especially in the 15-24 age group (Ministry of Health – Government of Uganda 2009:17). It was therefore important for the researcher to analyse mortality in terms of gender and age group, and this analysis determined the gender and age group in which the most deaths occurred in the hospital.

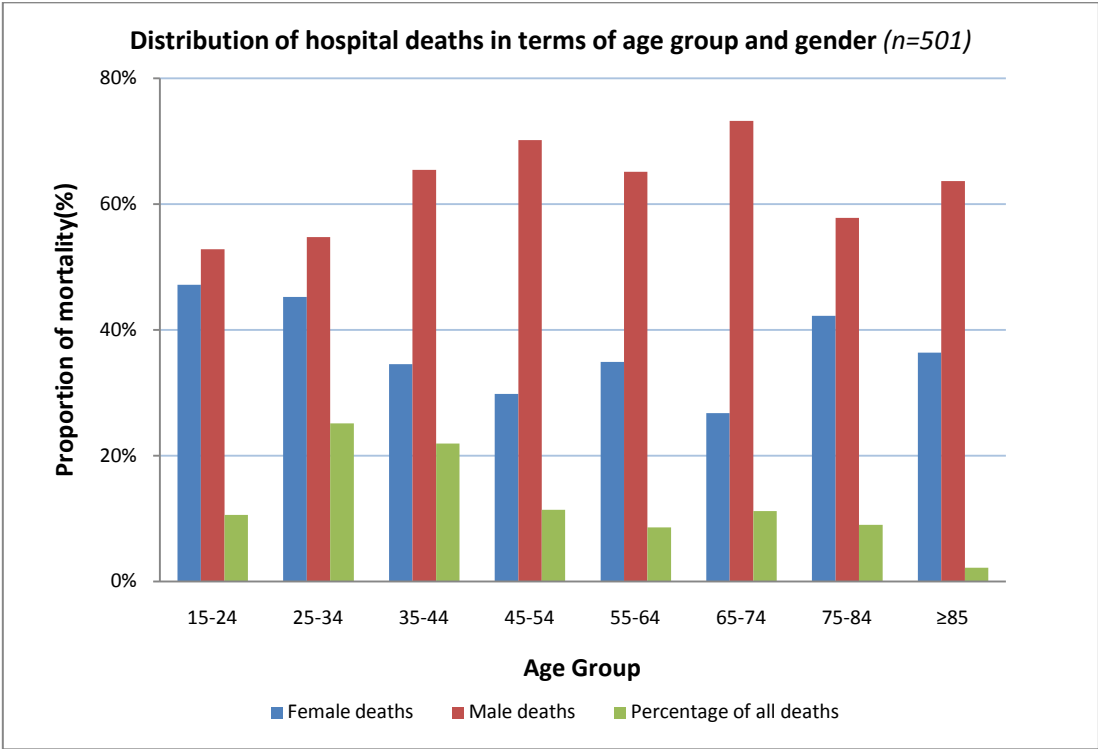


Figure 4.1: Distribution of hospital deaths in terms of age group and gender

More male deaths than female deaths occurred in the hospital in all the age groups that were examined. In the 45-54 and the 65-74 age groups, 70.2% (n=57) and 73.2% (n=56) of all the recorded deaths were those of males. The least difference between male and female mortality rates occurred in the 15-24 age group, in which 47.2% (n=53) of the deaths were female and 52.8% (n=53) were male respectively, while in the 25-34 age group, 45.2% (n=126) of the deaths were female and 54.8% (n=126) of the deaths were male.

Table 4.1 and figure 4.1 reveal that the high mortality in the 25-34 and 35-44 age groups was similar to those that are being revealed in findings from other studies and reports. In Uganda, the highest HIV prevalence was found among the 25-39 age group, with a peak prevalence of 10.3% in the 30-34 age group (Ministry of Health – Government of Uganda 2009:21,29; Uganda AIDS Commission – Government of Uganda 2008:12).

Figure 4.1 reveals that 30.0% (n=190) of the female deaths occurred in the 25-34 age group, 20.0% (n=190) in the 35-44 age group, and 13.2% (n=190) in the 15-24 age group. Among the males, 23.2% (n=311) of the deaths occurred in the 35-44 age group, 22.2% (n=311) in the 25-34 age group, and 9% (n=311) of the deaths occurred in the 15-24 age group.

The highest mortality rate occurred among females in the 25-34 age group and in the 35-44 age group among males. Therefore, proportionally more females died at a younger age compared to males. These findings further emphasize the findings as outlined in table 4.1, which shows that 43.2% of the female deaths and 31.2% of the male deaths occurred in the first twenty years of adulthood (in the 15-34 age group).

The high HIV prevalence in the age bracket 25-39 was therefore associated with high hospital mortality rate. While the highest number of deaths among females occurred in the 25-34 age group (30%), the highest number of male deaths occurred in the 35-44 age group (23.2%). This study showed that 43.2% of the female deaths and 31.2% of the male deaths occurred in the first twenty years of adulthood (in the 15-34 age group). Proportionally therefore more females died at a younger age when they mortality rates are compared to those of males. In all age groups, more males than females died in the hospital. The least proportional difference between the female and male mortality rates

occurred in the 15-24 age group, in which 47.2% of the deaths were those of females and 52.8% were those of males. The highest proportional difference between female to male mortality rates occurred in the 65-74 age group, in which 26.8% of the deaths were those of females while 73.2% were those of males.

4.4.2 Distribution of hospital mortality rates in terms of gender

The researcher analysed the mortality rates in terms of gender in order to determine the distribution of deaths in terms of gender and in order to find out which gender was most affected by mortality.

4.4.2.1 The distribution of hospital mortality rates in terms of gender

On a national level, the HIV prevalence among females in rural areas was 6.5% compared to an HIV prevalence of 4.8% among males living in the same areas (Uganda AIDS Commission – Government of Uganda 2006:6). In this study, the HIV prevalence of reference for the Mpigi district that was used for this analysis was the HIV prevalence of Central Uganda, which was 8.6% (10.4% for females and 6.4% for males) (Ministry of Health – Government of Uganda 2009:22).

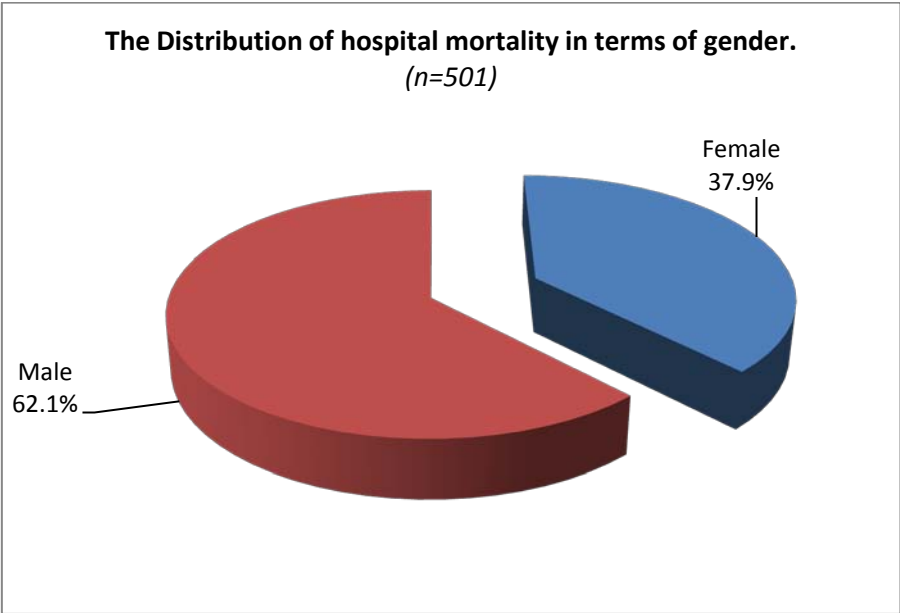


Figure 4.2: The distribution of hospital mortality in terms of gender

The researcher's analysis of 501 deaths that occurred over a period of six years is graphically depicted in figure 4.2 (above). It reveals that 37.9% and 62.1% of all the deaths that occurred were those of females and males respectively. Despite a higher prevalence of HIV in females than in males, more adult males than females died in the hospital. The United Nations estimates the proportion of mortality in terms of gender for Uganda at 1:1 (2005-2010) for males and females respectively (United Nations – Population Division of the Department of Economic and Social Affairs. 2009d:[1]). Although the expected male-to-female mortality ratio was therefore 1:1, the results of this study showed that the hospital mortality in terms of gender was 1.6 male deaths to every single (1) female death. The results of this study are similar to those of other studies that have also revealed a higher mortality in men than that of women in low-resource settings (Braga 2007:326; Nicastrì 2005:582).

More adult males therefore died in comparison to adult females – with a ratio of two (1.6) male deaths to every single (1) female death. Since this study focused on hospital deaths, this gender distribution of deaths raised the following questions:

- Firstly, what was the gender distribution of adult mortality for the deaths that occurred in the community (these deaths that were not reported in the formal health system and were not included in this study)? In other words, did more females compared to males die in the community?
- Secondly, why did more male deaths occur in the hospital? Was this factor influenced by access? Were more males with terminal illnesses accessing health services compared to females with terminal illness? These are issues that require further research.

4.4.2.2 Annual mortality trends in terms of gender

The variations in mortality were analysed by the researcher in order to determine any changes in annual mortality patterns in terms of gender that had occurred over the previous six-year period. The results of this analysis are presented in table 4.2 (below):

Table 4.2: Distribution of hospital deaths in terms of year of death and gender

Year of Death	Gender		Male deaths <i>n</i> (%)	Percentage annual increase (%)	TOTAL number of deaths <i>n</i> (%)	Percentage annual increase (%)
	Female deaths <i>n</i> (%)	Percentage annual increase (%)				
2002/03	31(40.3) (14.7)	-	46(59.7) (14.0)	-	77 (14.3)	-
2003/04	31(37.8) (14.7)	0.0	51(62.2) (15.5)	10.9	82 (15.2)	6.5
2004/05	36(46.2) (17.1)	16.1	42(53.8) (12.8)	-17.6	78 (14.4)	-4.9
2005/06	34(40.0) (16.1)	-5.6	51(60.0) (15.5)	21.4	85 (15.7)	9.0
2006/07	38(37.6) (18.0)	11.8	63(62.4) (19.1)	23.5	101 (18.7)	18.8
2007/08	41(35.0) (19.4)	7.9	76(65.0) (23.1)	20.6	117 (21.7)	15.8
Total	211(39.1)	(Av*) 6.0	329(60.9)	(Av) 11.8	540	(Av) 9.1

(n=540, Missing = 4) Av- Average*

Proportionally, the highest number of deaths that occurred during the six-year period that was covered by this study occurred in 2007/2008 (21.7%, n=540), which also happened to be the last year of the post-free ART era with the highest levels of ART coverage. This contrasted with the expectation that increased ART coverage would reduce hospital mortality rates. The least number of deaths occurred in 2002/2003 (14.3%, n=540) which is a year in the pre-free ART era.

In the six-year period covered by the study, the male mortality increased at twice the annual rate of increase in female deaths. An analysis of the two years of pre-free ART period showed that, on average, the male mortality decreased by 3.4% while female mortality increased by 8.1% annually. In the post-free ART era (2005/2006 to 2007/2008), male deaths (on average) increased by 21.7% annually while females deaths which increased by 4.6% annually.

The annual mortality changes by gender therefore reversed in the post-free ART era compared to the pre-free ART with male mortality increasing at 4.7 times the annual increase in female mortality. This rate of male mortality was therefore identified as an issue of concern that required further research.

4.4.3 The distribution of deaths in terms of sub-county of residence

The hospital that was the locus of this study serves a rural community with a population catchment area from the three sub-counties of Nkozi, Kituntu and Buwama sub-counties, which together form the Mawokota South health sub-district which is located in the Mpigi District. The health sub-district is neighboured by the Bulo, Kamengo, Maddu, Kabulasoke sub-counties in the Mpigi District and the Lukaya sub-county in the Masaka District (see section 1.2.2 for further details). Because of its location and the services that it offers, the hospital is accessible to all patients within and from outside the population catchment area. Apart from the physical accessibility of hospital services, the access to services is also determined by choice or preference (among other factors). It was therefore a matter of great significance for the hospital authorities and the district managers to determine the composition and nature of the population that was being served by the facility, and, in this case, to analyse mortality rates in terms of the different geographical areas from which patients were admitted.

The distribution of the deaths in terms of the location of the patient's residence (i.e. the patient's home) will enable managers to design appropriate and targeted financial and programmatic interventions that will ensure that the hospital will be able to meet the expectations that populations have with regard to services. Population distribution in terms of places of residence also enables managers to establish and maintain regular communication with local community leaders. Communications with communities served by the hospital ensures that the health challenges that the communities face can be adequately explained at a local level and so that suggestions can be made about how such health challenges can be met and ameliorated.

4.4.3.1 Mortality in terms of sub-county of residence

It has been reported by the WHO that "only 49% of the households [in Uganda] have access to health care facilities" (WHO 2001:[1]). Because the locations of the sub-county of residence of all patients is a key determinant of access to health care (because the sub-county of residence indicates the distance that a patient has to travel to get to the hospital), the researcher was also determined to analyse mortality rates in terms of the sub-county of residence. Hospital deaths from Mawokota South health sub-district (which comprise the Nkozi, Buwama and Kituntu sub-counties) and the four

neighbouring sub-counties were duly analysed. Since the number of recorded deaths from other sub-counties such as Budde, Ngando, Kyegonza were few in number, the researcher categorised them under the blanket heading of “other sub-counties”.

Table 4.3: Distribution of mortality in terms of sub-county of residence and gender

Sub-County	Female deaths <i>n (%)</i>	Male deaths <i>n (%)</i>	TOTAL number of deaths <i>n (%)</i>
Bulo	5(31.3) (2.5)	11(68.7) (3.5)	16 (3.1)
Buwama	31(36.9) (15.5)	53(63.1) (17.1)	84 (16.5)
Maddu	6(46.2) (3)	7(53.8) (2.3)	13 (2.5)
Kabulasoke	2(50) (1)	2(50) (0.6)	4 (0.8)
Kamengo	11(33.3) (5.5)	22(66.7) (7.1)	33 (6.5)
Kituntu	49(38.3) (24.5)	79(61.7) (25.5)	128 (25.1)
Nkozi	79(43.6) (39.5)	102(56.4) (32.9)	181 (35.5)
Other sub-counties	17(33.3) (8.5)	34(66.7) (11.0)	51 (10)
TOTAL	200(39.2)	310(60.8)	510

(n=510, missing - 34)

Table 4.3 indicates that 35.5% (n=510) of all deaths occurred in the Nkozi sub-county, 25.1% (n=510) occurred in the Kituntu sub-county, and that 16.5% (n=510) occurred in the Buwama sub-county. These findings reveal that 77.1% (n=510) of all hospital deaths were those of patients who lived *within* the hospital catchment population. The results also show that, only 22.9% (n=510) of the number of deaths that occurred were of patients who came from sub-counties *outside* the hospital catchment area.

Among the sub-counties that were classified as being outside hospital catchment area, Kamengo recorded the highest number of deaths, with 6.4% (n=510) of these deaths occurring in the hospital. The deaths from Bulo (3.1%), Maddu (2.5%), Kabulasoke (0.8%) and the other sub-counties (10%) were too few in number for significant analysis. They were however useful for providing a breakdown of the sub-counties of residence of the patients who accessed the services of the hospital and the number of deaths that occurred in terms of the sub-county of residence of the patients concerned.

As one might expect, the people who lived within the sub-county of the hospital enjoyed the best degree of physical access to the hospital in comparison to all those people from other sub-counties (who, according to the findings of the study) constituted the majority of this sample. In all the sub-counties, the number of male deaths was proportionally higher than the number of female deaths. The female-to-male proportions from the different sub-counties was more or less similar, with 61.7% (n=128), 56.4% (n=181) and 63.1 (n=84) of the recorded deaths being those of male patients from the Kituntu, Nkozi and Buwama sub-counties respectively.

In summary, the highest number of deaths from the Mpigi District that occurred in the hospital were of Nkozi sub-county (35.5%, n=510) residents, followed by those from Kituntu sub-county (25.1%, n=510), and those from Buwama (16.5%, n=510) sub-county. The least number of deaths among patients were recorded among those from Kabulasoke sub-county (0.8%, n=510). These findings show that the 77.1% (n=510) of all the hospital deaths that occurred during the study period were from the hospital's population catchment area while 22.9% (n=510) of the patients who died in hospital came from outside the hospital's defined catchment area. It is also noteworthy that more males than females from all sub-counties died in the hospital.

4.4.3.2 Mortality in terms of sub-county of residence and treatment era

In this study, the researcher analysed mortality rates, not only in terms of residence but also in terms of the treatment era in which the patients died (whether in the pre-free or post-free ART eras). The researcher therefore compiled a comparison of the proportion of deaths in terms of sub-county of residence as well as in terms of the pre-free and post-free eras in which the deaths occurred. This analysis was carried out in order to determine the changes (if any) in the mortality (number and proportion of deaths) in the pre-free ART era in comparison to those of the post-free ART era. Table 4.4 (below) presents the findings for these variables.

Table 4.4: Hospital deaths in terms of sub-county of residence and treatment era

Sub-County	Pre- free ART deaths <i>n (%)</i>	Post- free ART deaths <i>n (%)</i>	TOTAL Number of deaths <i>n (%)</i>	Variance <i>(% Change in number of deaths from the sub-county)</i>
Bulo	8(50) (3.6)	8(50) (2.7)	16 (3.1)	-0.9
Buwama	42(49.4) (18.9)	43(50.6) (14.7)	85 (16.6)	-4.2
Maddu	7(53.8) (3.2)	6(46.2) (2.1)	13 (2.5)	-1.1
Kabulasoke	1(25) (0.4)	3(75) (1)	4 (0.8)	0.6
Kamengo	11(33.3) (5)	22(66.7) (7.5)	33 (6.4)	2.5
Kituntu	49(38.0) (22.1)	80(62.0) 27.4	129 (25.1)	5.3
Nkozi	90(49.2) (40.5)	93(50.8) (31.9)	183 (35.6)	-8.6
Other Sub-Counties	14(27.5) (6.3)	37(72.5) (12.7)	51 (9.9)	5.4
TOTAL	222(43.2)	292(56.8)	514	13.6

(n=514, missing - 30)

These findings reveal that 56.8% (n=514) of the deaths occurred in the post-free ART era in comparison to the 43.2% (n=514) of deaths that occurred in the pre-free ART era – representing a 13.6% higher proportion of deaths in the post free-ART era. (These findings are further analysed in figure 4.3 below.)

Absolute numbers and percentages of mortalities indicated the difference in the proportion of deaths in the pre-free and post-free ART eras in terms of sub-county. In spite of this, the most appropriate measure of hospital mortality trends was accomplished by an analysis of the mortality rates (number of deaths per 100 hospital admissions) that is described in section 4.5.3.4.

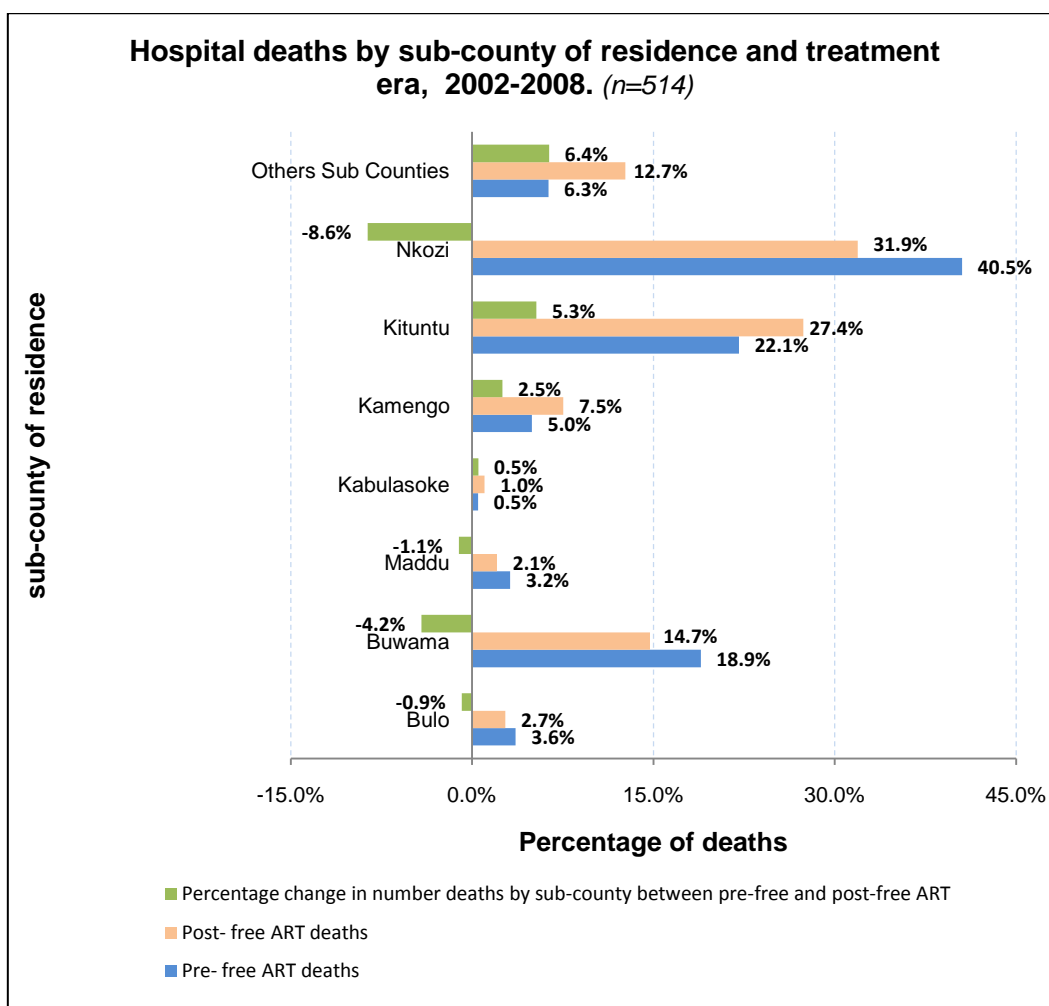


Figure 4.3: Hospital deaths by sub-county of residence and treatment era (2002-2008)

The findings set out in table 4.4 and figure 4.3 (above) indicate that when one compares the post-free ART era to the pre-free ART era, the number of deaths from Nkozi and Buwama sub-counties declined by 8.6% (n=183) and 4.2% (n=85) respectively. This was a noteworthy reduction in the proportion of deaths from these sub-counties in the population catchment area. The additional finding that partially explained this reduction in mortality in the two sub-counties of Mawokota South (when compared to the other sub-counties that the researcher analysed in this study) was that Nkozi and Buwama sub-counties, possessed one authorised ART-provision site each (Ministry of Health – Government of Uganda 2009:45). These two ART sites had been established in the Nkozi Hospital and the Buwama Health Centre in Nkozi and Buwama sub-counties, and had been providing free ART since July 2005 and January 2007 respectively. By June 2008, the Nkozi Hospital and the Buwama Health Centre reported that they had

cumulatively provided ART to 495 and 287 patients (respectively). It was these two ART sites that facilitated patient access to ART in the Mawokota South county, and this, in turn, contributed to the recorded reduction in the mortality rates of the post-free ART era in these two sub-counties.

Proportionally, the number of deaths from Kituntu, other sub-counties and Kamengo increased in the post-free ART era by 5.3% (n=129), 6.4% (n=51) and 2.5% (n=33) respectively. Since these sub-counties had no established free ART access clinics, patients from these sub-counties obviously encountered many more obstacles in their attempts to access free ART, and it is this factor (the absence of ART-distribution sites in their sub-counties) that may have contributed to the increase in mortality rates in these sub counties that became evident in the post-free ART era.

It is therefore clear that increased access to free ART in Nkozi and Buwama sub-counties contributed to the 8.6% (n=183) and 4.2% (n=85) decline in the mortality rates in Nkozi and Buwama sub-counties respectively. Mortality in sub-counties which did not have a designated free ART site (such as those in Kituntu and Kamengo sub-counties) *increased* by 5.3% (n=129) and 2.5% (n=33) respectively.

4.4.4 Statistical correlations between mortality and place of residence

Access to ART services and other general health services are influenced by the distances between the patients' homes and the health facility, the cost of transport, and by gender. The population that resides in the hospital catchment area obviously lives much closer to the hospital and is therefore much more likely to be better informed about available services such as free ART programmes and the other services offered by the hospital. The population that lives in closer proximity to the hospital will also need to spend far less on transport in order to get to the hospital and to access its programmes (such as ART) and other services.

As one may therefore expect, the majority of deaths that occurred in the hospital were those of patients from the hospital's catchment area. In the post-free ART era, observers expected that an increased access to ART in the health care would cascade into more adults accessing ART and that this, in turn, would contribute to a significant reduction in the rates of hospital adult mortality. Figure 4.3 shows how the number of

deaths from the Nkozi and Buwama sub counties did, in fact, decline. The challenge for the researcher inherent in this observation was to determine whether or not the proportional reduction in number of deaths was statistically significant.

4.4.4.1 Mortality in terms of sub-county of residence and treatment era

In order to determine the association between sub-county of residence and mortality, the researcher divided (categorised) all the deaths into two groups the following: (a) the number of deaths that had occurred among residents in the Mawokota South health sub-district (the Nkozi, Buwama and Kituntu sub-counties within the catchment area), and (b) the number of deaths that occurred among residents of other sub-counties (outside the catchment area). The researcher accomplished the analysis of the association between the risk of mortality in terms of residence and in terms of gender by using a two by two contingency table, and the results that he obtained are discussed below.

Table 4.5: Association between mortality in terms of residence and treatment era

Sub-county of Residence	Treatment Era		TOTAL number of deaths <i>n (%)</i>
	Post- free ART deaths <i>n (%)</i>	Pre- free ART deaths <i>n (%)</i>	
Mawokota County	216(54.4) (74.0)	181(45.6) (81.5)	397 (77.2)
Other counties	76(65.0) (26.0)	41(35.0) (18.5)	117 (22.8)
TOTAL	292(56.8)	222(43.2)	514

(n=514, missing - 30)

The distribution of the hospital mortality in terms of residence and treatment era set out in table 4.5 (above) show that, in the post-free ART era, there was a proportionally lower number of deaths that occurred in Mawokota County. The number of deaths that occurred from Mawokota South declined by 7.5% from 81.5% (n=222) in the pre-free ART era to 74.0% (n=292), in comparison to the number of deaths that occurred from other counties, which increased by 7.5% from 18.5% (n=222) to 26.0% (n=292).

The findings that are set out in table 4.5 (above) also indicate that, in the post-free ART era, there was a diminished likelihood that a patient from a Mawokota South health sub-district would die in the hospital when one compares with the pre-free ART era. The likelihood that a patient from Mawokota would die in hospital was therefore reduced by 10.6% (a risk difference of 10.6%, 95% CI[-20.5%-0.6%]; OR=0.64, 95% CI[0.42-0.98]; RR=0.84, CI[0.71-0.98]). An association was therefore evident between a patient's place of residence and the treatment era in which the death occurred since patients from the Mawokota South health sub-district residents had lower odds of death in the hospital in the post-free ART era compared to those they had in the pre-free ART era ($\chi^2=4.10$; $p=0.043$). As was pointed out earlier in this chapter, the Nkozi and Buwama sub-counties had designated free ART sites and health clinics in these sub-counties had already been providing free ART from July 2005 and January 2007 respectively.

One may therefore note that, in the post-free ART era, the residence of a patient in the hospital catchment area which had increased access to free ART was associated with a reduced likeliness of death in the hospital. In the post-ART era, an increased access to ART in the catchment area therefore contributed to a 10.6% reduction in the likelihood (risk) that a patient who lived in the population catchment area would die in the hospital.

4.4.4.2 Female mortality in terms of county of residence

After the researcher had determined the significance of the association between treatment era and county/sub-county of residence, he engaged in a further analysis to determine the significance of gender differences in hospital mortality in terms of place of residence.

In order to determine variations in mortality rates in terms of gender and place of residence, the researcher analysed female and male deaths from within the hospital's catchment area of the hospital and from outside the catchment. A two by two contingency table took account of the treatment era (whether the pre-free or the post-free ART era) and the analysis for statistical association was accomplished and presented below.

Table 4.6: The association between female mortality and county of residence

County of Residence	Treatment Era		TOTAL number of deaths <i>n (%)</i>
	Post-free ART deaths <i>n (%)</i>	Pre-free ART deaths <i>n (%)</i>	
Mawokota South County	85(53.5) (78.7)	74(46.5) (80.4)	159 (79.5)
Other Counties	23(56.1) (21.3)	18(43.9) (19.6)	41 (20.5)
TOTAL	108(54.0)	92(46.0)	200

(n=200, missing - 11)

The findings set out in table 4.6 revealed that, among females who had resided in Mawokota South county, there was a 1.7% reduction in the proportional mortality from 80.4% (n=92) in the pre-free ART era to 78.7% (n=108) in the post-free ART era. But this reduction was not statistically significant ($\chi^2=0.09$; $p=0.76$).

This means that whether the deceased females had been admitted in the pre-free ART era or in the post-free ART era, they were faced with an equal likelihood of hospital death if they were residents of the Mawokota South health sub-district residents. One may therefore conclude that free access to ART exerted no significant effects on female hospital mortality in terms of their place of residence.

4.4.4.3 Male mortality in terms of county of residence

After the researcher had analysed the female pre-free and post-free ART era mortality in terms of county of residence, he proceeded to apply the same techniques in order to determine whether there was any significant difference in the male pre-free and post-free ART-era mortality in terms of county of residence.

Table 4.7: The association between male mortality and county of residence

Sub-county of Residence	Treatment Era		TOTAL number of deaths n (%)
	Post- free ART deaths n (%)	Pre- free ART deaths n (%)	
Mawokota County	129(55.1) (70.9)	105(44.9) (82.0)	234 (75.5)
Other Counties	53(69.7) (29.1)	23(30.3) (18.0)	76 (24.5)
TOTAL	182(58.7)	128(41.3)	310

(n=310, missing-29)

In contrast to what was discovered about the female deaths, the researcher found that the number of male deaths from Mawokota South county residents declined by 11.1% from 82.0% (n=128) in the pre-free ART era to 70.9% (n=182) in the post-free ART era. This reduction was statistically significant ($\chi^2=5.05$; $p=0.024$). As far as males were concerned, in the post-free ART era, the possibility (risk) of a male hospital death of a resident of the Mawokota South health sub-district, declined by 14.6% (95% CI[-26.8%--2.5%]; OR=0.53, 95% CI[0.31-0.93];).

Therefore, the provision of free access to ART in Mawokota South health sub-district was associated with a reduced likelihood of male hospital death among males from the hospital's catchment area.

4.4.5 Average length of stay and out-of-pocket payments

In a study that was undertaken in Botswana, the most important barrier to adherence to ART was the cost of ARVs. In a modelling that eliminated cost as a factor in the process of accessing ART, the researchers projected that adherence to ART would increase from 54% to 71% (Wilson & Fairall 2008:485). But in spite of the fact that there is free access to ART, the various costs associated with health services remain a key barrier to ART access, especially for the poorer sector of the population and for those who live some distance away from ART access sites.

The length of a patient's hospital stay is a critical factor in calculating the cost of services to the patients concerned and to the hospital. The objective of free access to ART is to reduce morbidity and mortality rates in high-prevalence settings. In such high-

prevalence settings, free access to ART is expected to reduce the number of admissions and the number of days spent in the hospital, especially in the case of HIV/AIDS-related diseases. This downward trend in morbidity is expected to be directly related to reduction in cost of service delivery for both the hospital and to the patients.

As part of this research, the researcher analysed the average length of stay (ALOS) in the hospital and the out-of-pocket payments that were made by patients who died in hospital during the research period. He also analysed the factors that were associated with out-of-pocket payments in both the pre-free and post-free ART eras. A further analysis to assess the correlation between factors associated with out-of-pocket was also undertaken and discussed.

4.4.5.1 *The average length of hospital stay before death occurred*

This study has reviewed the number of admission days before death, the ALOS in hospital, and median number of admission days. The analysis of the number of admission days before death intervened was obtained by subtracting the date of admission from the date of death in order to determine the total number of days that were spent in hospital. The actual time of admission and the time of death were not used in this analysis to determine the exact number of hours that the patient spent in hospital before his or her death. The result was a discrete number of days of admission – days that ranged from a minimum number of zero (0) days (implying that death had occurred within one day (24 hours) of admission), to the highest number of admission days.

In this analysis, the researcher categorised the number of admission days into the following four categories:

1. less than or equal to one day of admission
2. two to three days (2-3) of admission
3. four to five days (4-5) of admission
4. more than five days of admission

The analysis of the number of days of admission before the patient's death was important for determining the severity of the illnesses with which patients presented on

admission to the hospital. The average number of days of admission was also important for determining the time that was available to health workers to investigate, diagnose and manage the patient before he or she died. By analysing the number of days before patient death, the researcher was also able to suggest how targeted health promotion efforts could be implemented in the community in order to encourage patients to obtain access to hospital services before their conditions became so acute that the risk of imminent death intervening very soon after admission became very high indeed.

The researcher analysed the number of hospital admission days in hospital before patient death, and presented his findings as follows:

Table 4.8: Number of admission days spent in hospital before death occurred

Number of admission days before death occurred	Frequency	Percentage % (95% Confidence Limits)	Cumulative percentage of frequencies %
≤1 days	135	27.6 (23.7-31.8)	27.6
2-3 days	155	31.6 (27.6-36.0)	59.2
4-5 days	130	26.5 (22.7-30.7)	85.7
>5 days	70	14.3 (11.4-17.8)	100.0
Total	490	100.0	

(n=490, missing-54)

The results show that 27.6% (n=490; 95% CI [23.7% - 31.8%]) of the deaths occurred within one day (or 24 hours) of admission while 31.6% (n=490; 27.6-36.0) of the deaths occurred within two to three days of admission to hospital.

These findings are set out on the graph below, and demonstrate the frequency of deaths in terms of the number of days of admission that elapsed before death intervened.

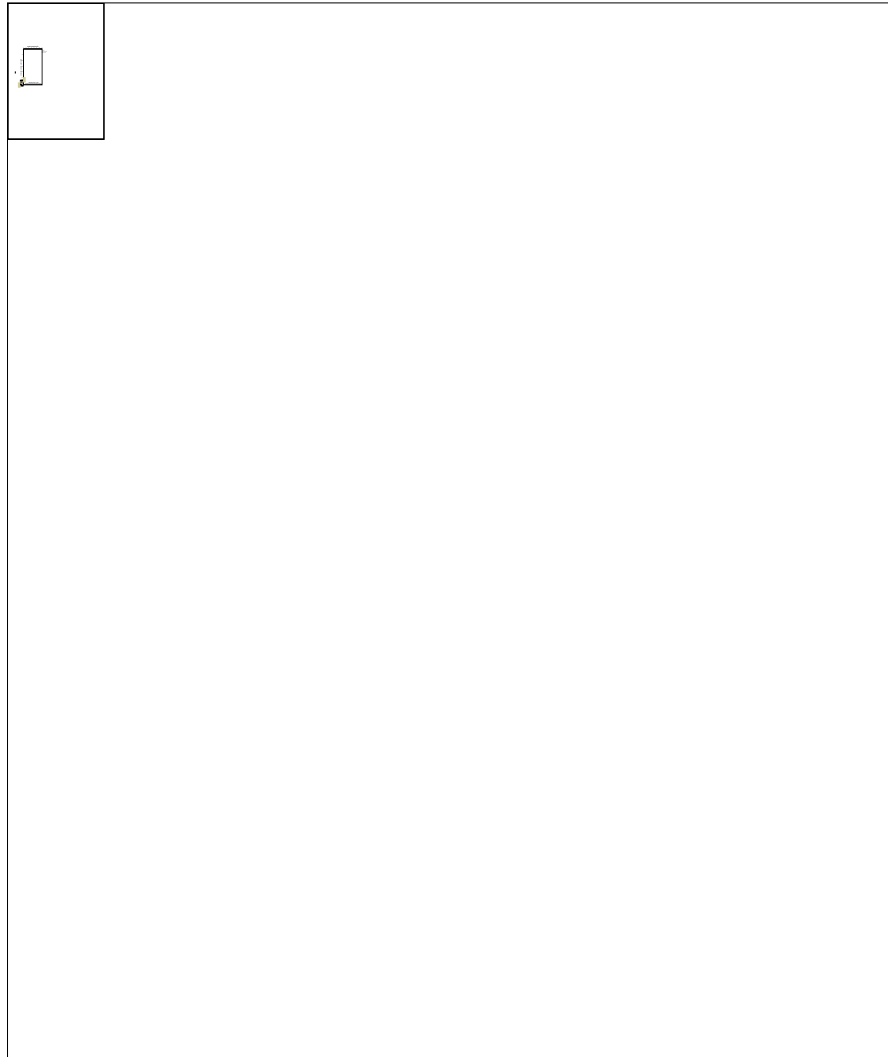


Figure 4.4: Number of admission days before death in Mawokota South (2002-2008)

It is evident from these figures that the shortest period of hospital stay before death was less than a day while the longest period of hospital stay in this study was 67 days. In total, 59.2% (n=490) of the patients died within three days of admission to hospital while 85.7% (n=490) of the patients died within five days of admission.

There was notably high mortality on the first day (the first 24 hours) and within three days of admission (see table 4.8 and figure 4.4). There was limited time for hospital staff to examine, manage and observe the patient before death intervened. This finding indicates that patients presented with severe and critical illnesses and conditions upon admission, which may have been largely due to late presentation to the hospital. This factor (late presentation to hospital) contributed to the high mortality rate on the first day

of admission. In many cases, the hospital staff did not even have opportunities to properly investigate the patient's causes of morbidity and subsequent mortality, and this frequently resulted in inadequate and incomplete investigations and therefore mortality records were incomplete in terms of a fully investigated and appropriately managed death event.

This high mortality on the first day of admission is similar to findings observed in the research conducted by Garko, Ekweani and Anyiam (2003:69) in Nigeria, where they found that 30% of all deaths occurred on the first day of admission. In this same Nigerian study, 65% of the deaths occurred within five days of admission in comparison to the 85.7% (n=490) of deaths that the present researcher identified in his Ugandan study (Garko et al 2003:69). In this study, mortality on the fifth day of admission is 20.7% higher than the mortality on the fifth day of admission in the study undertaken by Garko et al in Nigeria. It is, however, important to note that the study in Nigeria was conducted in a tertiary hospital whereas the Uganda study was conducted in a district hospital.

The shortest period of hospital stay before death was therefore less than one day while the longest period of hospital stay identified in this study was 67 days. The highest mortality among patients occurred on the first day of admission, with 27.6% (n=490; 95% CI [23.7% - 31.8%]) of the deaths occurring within one day (24 hours) of admission while 31.6% (n=490; 27.6-36.0) occurred within two to three days of admission. Overall, 59.2% (n=490) of the patients died within three days of admission and 85.7% (n=490) of the deaths occurred within five days of admission.

4.4.5.2 Average length of stay in the pre-free and post-free ART eras

The ALOS for patients in this study was calculated by the using the total number of inpatient days for all deaths, which were determined by subtracting from the date of admission from the date of death, and then by dividing the total number of days spent in hospital by the total number of deaths that occurred per annum (Pennsylvania Department of Health 2001:[1]; European Union Public Health Information System – EUPHIX 2009:[1]).

Table 4.9: The average length of hospital stay in Mawokota South (2002-2008)

	Average length of stay before death ($n \pm SD$)	Mortalities reviewed
2002/03	6.0±9.5	74
2003/04	4.2±4.4	81
2004/05	4.1±4.4	69
2005/06	3.9±4.4	72
2006/07	5.1±5.3	89
2007/08	6.0±9.7	105
Average	4.9±6.9	

($n=490$, missing 54) *SD-Standard Deviation*

The findings set out in table 4.9 (above) show that the ALOS in this study was 4.96 days. These findings were similar to the ALOS that was identified in another study undertaken in Nigeria that reported an ALOS in hospital of 4.95 days before death occurred (Yisa et al. 2004:69). It is therefore evident that the overall ALOS in hospitals in this rural setting falls within earlier reported limits that have been reported by other similar studies.

In terms of a simple average, the ALOS before death in the pre-free ART era was 4.8 days while, in the post-free ART era, it was five days.

The overall ALOS before death in the hospital was five days, with 4.8 days before death in the pre-free ART era and 5 days before death in the post-free ART era. It is therefore evident that free access to ART had not reduced the ALOS before death in a hospital.

4.4.5.3 The trend of the average number of admission days before death

In order to determine the ALOS before death trends over the six-year period of the study, and to provide a basis for projecting future ALOS trends, the researcher exponentially smoothed the annual ALOS with a dumping factor of 0.8 in the line graph below.

Hospital efficiency factors are dependent upon factors such as the number of health workers (nurses, medical doctors and other health workers) and their skills and approaches to the management of health systems. Other factors that are critical in enhancing the efficiency of the way in which the hospital manages its patients and

which have an impact on the ALOS before death include the availability and functionality of diagnostic equipment, and the speed with which patients were able to gain access to emergency care and referral services.

Apart from hospital factors, patient factors play a significant role in determining the ALOS before death. As discussed earlier in 4.4.5.1, late presentation of patients for hospital care is a key determinant of ALOS in hospital.

Since ALOS is a measure of efficiency with which a hospital system is able to manage and refer patients to minimise the risk of death, the dumping factor of 0.8 ensured that a greater weight was given to the most recent practices and conditions that had been implemented in the hospital to improve the efficiency with which patients are managed. The researcher therefore gave less weight to earlier practices and conditions, therefore, these findings and projections closely resemble the features that will be evident in future trends.

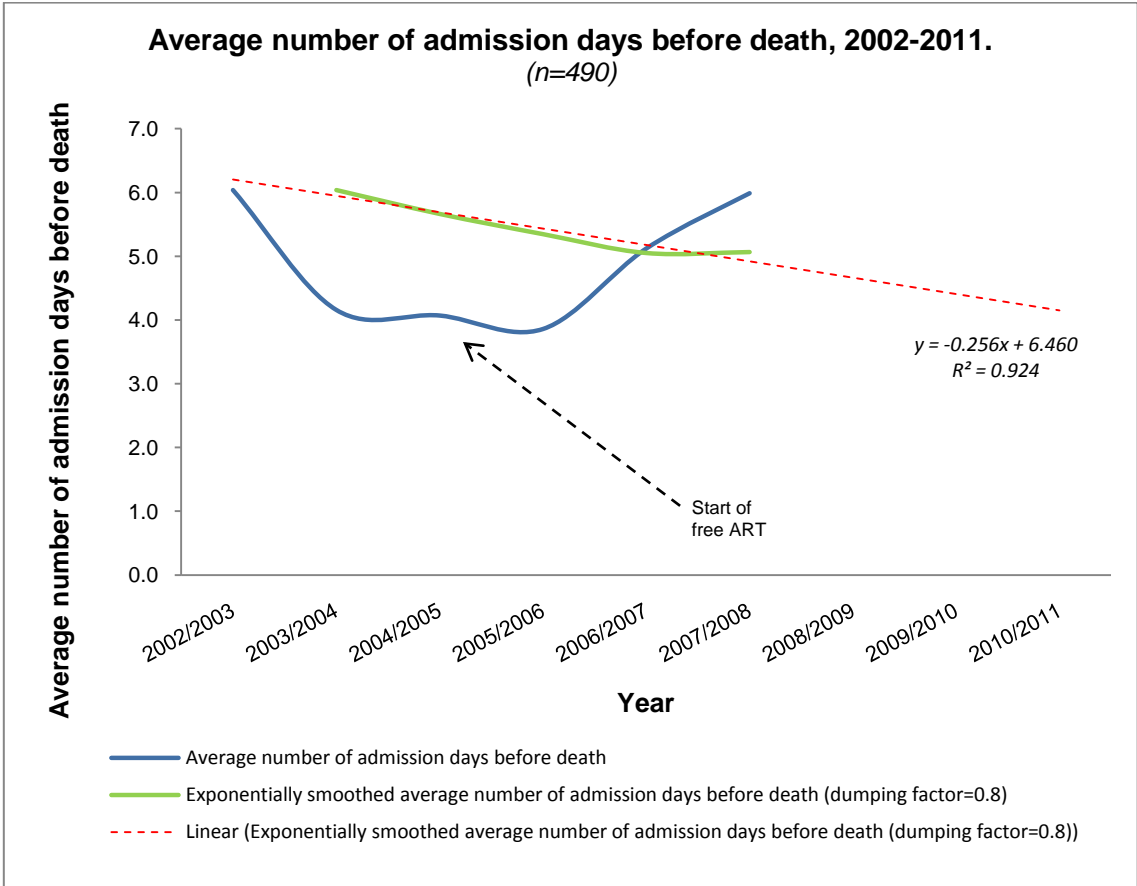


Figure 4.5: Average number of admission days before death (2002-2011)

A review of 490 deaths and an analysis of ALOS before death shows that in 2002/2003, the average number of admission days before death was six days, and that this average figure progressively reduced to five days in 2007/2008. The researcher projected that the ALOS would reach four days of admission before death intervened by June 2011.

The ALOS before death therefore demonstrated a decreasing trend. This finding in a way compliments findings in section 4.4.5.1 that are indicative of the increasing number (percentage) of patients who were being admitted to hospital with critical or severe illnesses that caused their death in progressively fewer days of hospital stay. The reduction in ALOS is also an indication of the capacity of the hospital to use its human resources, equipment, medicines and management systems to manage critical illnesses as well as its capacity for referring refer critically ill patients to other levels of care to reduce the risk of mortality. In this study therefore, reductions in the ALOS before death is an indicator of the challenges that the hospital is facing as it tries to contain or reduce mortality rates.

The determination of the degree of efficiency with which the hospital was able to manage inpatients was beyond the scope of this study, but it would offer a fruitful area of study for future researchers.

4.4.5.4 *The median number of admission days before death*

Because of the risks associated with the measurement of the ALOS before death in the hospital, that are caused by *outlier* values on both extremes of the spectrum (values that could affect the accuracy of the mean as a measure of central tendency), the researcher decided to use the median number of admissions days as a better measure of central tendency. He therefore used the median number of days of admission to determine the trend in median admission days per annum and this enabled him to make a comparison between the pre-free and post-free ART eras.

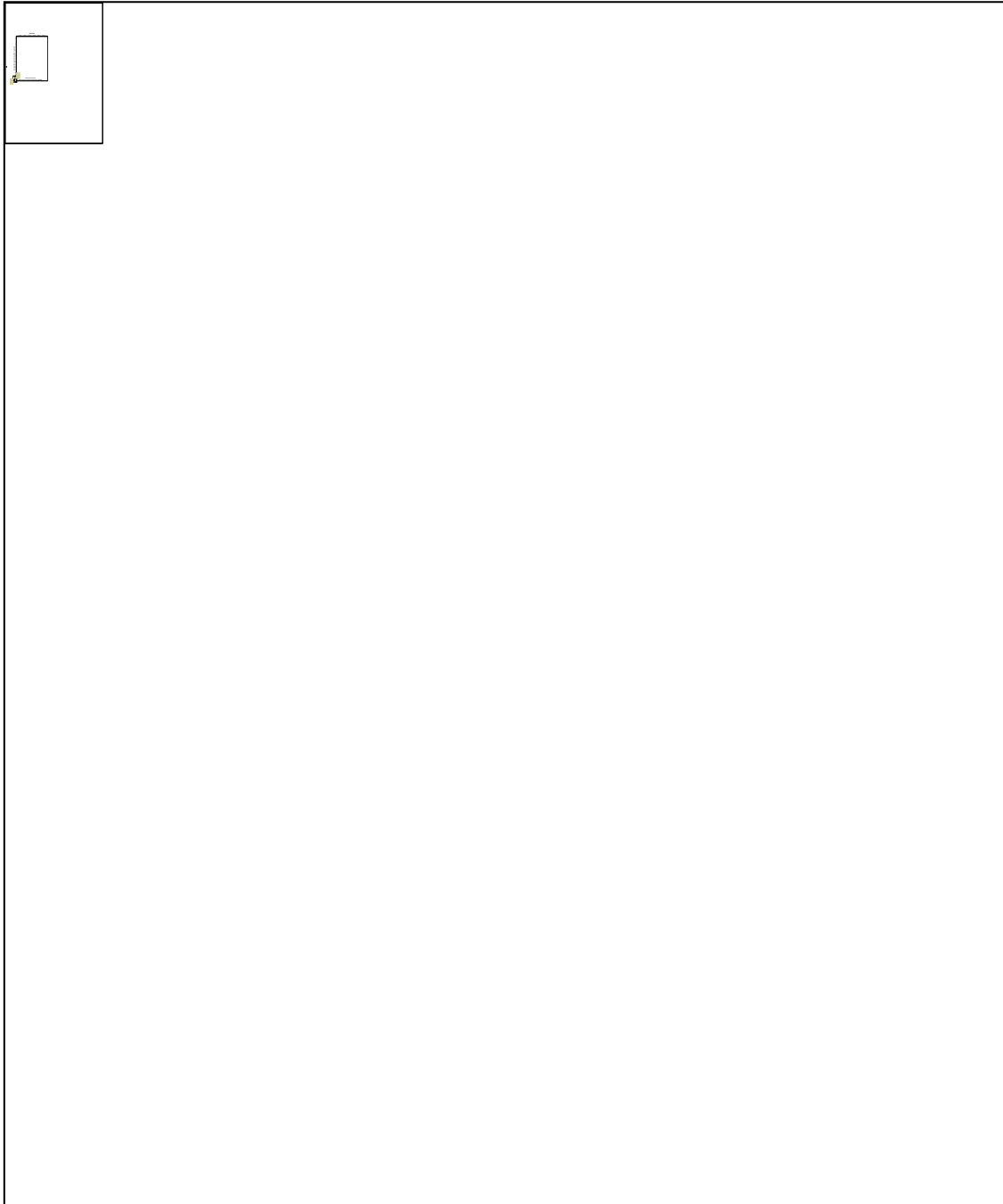


Figure 4.6: The median number of admission days before death (2002-2008)

Figure 4.6 shows that, the median number of admission days before death, remained constant at three days of admission during the pre-free ART era but increased to four days in 2006/2007 before it fell back to three days in 2007/2008(a period that represented the pre-free ART era).

There was therefore no change in the median number of admission days in the three pre-free ART era years compared to the three years of the post-free ART era. There

was, however, there was an increase in variation (between the minimum and maximum number of days of admission) of the number of admission days in the 2007/2008 period. This was indicative of the increasing number of chronic conditions among those who were being admitted to the hospital and who were remaining in the hospital for prolonged periods before their death. Specific conditions that fell into this category were frequently observed in HIV-related conditions such as TB. Among the top 15 patients who spent the longest time in hospital before death, three of them were TB patients, and these three spent 67, 45 and 26 days in hospital respectively before their deaths.

These findings showed that increased access to ART did not affect (i.e. did not either reduce or prolong) the median length of hospital stay for patients who died in the hospital.

4.4.6 Out-of-pocket payments for hospital services

In the rural setting of the Mpigi district, patients endured a variety of costs during the process of accessing health care. Out-of-pocket payments allow a researcher to make an estimate of the direct cost of health service delivery to service providers and to patients. Although out-of-pocket payments are the main form of payments for most health services in developing countries, they also constitute a key barrier to health care for poor families (Forgarty International Centre of the United States [U.S] National Institutes of Health, The World Bank, WHO, Population Reference Bureau, Bill and Melinda Gates Foundation 2007:4). In this study, the researcher made a record of all the out-of-pocket payments that were made by patients before their death from medical records before analysing them. As has already been pointed out earlier in this text, out-of-pocket payments in Uganda are also referred to as “user fees” or “user charges”. The researcher therefore analysed the trends and patterns of out-of-pocket payments and sought to find a meaningful association between out-of-pocket payments and the number of hospital deaths that occurred in the pre-free and post-free ART eras.

Although out-of-pocket-payments included the cost of medicines, medical sundries, laboratory fees and consultation fees, they excluded other costs that were incurred by the patient during the process of accessing health care – costs such as transport to and from the hospital, the cost of food and revenue that was lost because of absence from work or family business.

4.4.6.1 Average of out-of-pocket payments per death

For each adult death, the researcher entered the total amount of hospital fees or charges that each patient paid in Uganda Shillings into the data analysis database and then proceeded with the analysis. For comparability across years, Uganda Shillings were converted into United States of America dollars (US\$). Since the exchange rates between Uganda Shillings and US\$ varied significantly over the six years of the study, the historical annual average exchange rate of one (1) US\$ to Uganda Shillings (by year) was determined and was thereafter used for converting Uganda Shillings into an equivalent amount of US dollars. The researcher rounded off the Uganda Shilling values and their US\$ equivalents to the nearest single decimal point. The historical rates showed that one US\$ equivalent to Uganda Shillings was 1 807.5 in 2002/2003, 1 995 in 2003/2004, 1 800.9 in 2004/2005, 1 899.1 in 2005/2006, 1 883.2 in 2006/2007, and 1 776 in 2007/2008 (OANDA Corporation 1997:[1]).

By using this approach to establish a rational exchange rate that would serve for the period under study, the researcher was able to give values to out-of-pocket rates and then perform a trend analysis that would guide the discussion.

Table 4.10: The trend of out-of-pocket payments per death (2002–2008)

Year	Average out-of-pocket payment per death (\pm SD*) (in US\$)	Median out-of-pocket payment per death (in US\$)	Range (Minimum-Maximum)	Number of deaths reviewed
2002/2003	10.1 \pm 7.1	9.4	1.7-44.8	72
2003/2004	9.3 \pm 9.9	8.5	1.5-80.2	74
2004/2005	9.6 \pm 6.2	9.4	1.7-29.4	76
2005/2006	9.5 \pm 5.3	10.5	2.1-26.3	76
2006/2007	12.7 \pm 8.6	10.6	1.6-65.3	96
2007/2008	16.3 \pm 12.5	14.1	1.9-84.5	108
Average	11.3 \pm 8.3	10.4	1.7-55.1	502

*SD-Standard Deviation, (n=502, missing-42)

The average out-of-pocket payment in the pre-free ART era was US\$ 9.7 (the average of 10-12002/2003, 9.3-2003/2004 and 9.6-2004/2005) compared to US\$ 12.8 (average of 9.5-2005/2006, 12.7-2006/2007 and 16.3-2007/2008) per death in the post-free ART

era. Over the six years of the study, the overall average out-of-pocket payment per death was US\$ 11.3 (ranging from the lowest out-of-pocket payment of US\$ 9.3 in 2003/2004 to the highest payment of US\$ 16.3 in 2007/2008). Out-of-pocket payments increased by 61.4% from US\$ 10.1 in 2002/2003 to US\$ 16.3 per death in 2007/2008. In the post-free ART era, the average out-of-pocket payment increased steadily from US\$ 9.5 to US\$ 16.3 per death.

In research undertaken in Thailand, the average inpatient cost per episode for diarrhoea was US\$ 76.8, of which US\$ 58.8 (77%) was consumed by hotel costs (Riewpaiboon, Intraprakan & Phoungkatesunthorn 2008:446). The other costs that were identified in the study included those that were made for meals, medical and nursing care, laboratory services, drugs and medical supplies. Apart from the hotel costs, the cost of the other services in the Thailand study (that is, the cost of the medical items, the laboratory services and health care) were US\$ 18 per episode of diarrhoea. In Zimbabwe, the cost of inpatient care for malaria and tuberculosis were US\$ 28 and US\$ 33 respectively (Hongoro & McPake 2003:248).

These references to the research undertaken in Thailand and Zimbabwe provided the researcher with a basis of comparison for average out-of-pocket payments in other settings, and enabled him to evaluate how the findings of his study compared with the parameters reported by estimates from other studies.

The findings in this study show that the out-of-pocket of US\$ 11.3 for the ALOS before death of 4.9 days (see table 4.9) was comparatively less than the out-of-pocket payments that patients needed to make in Thailand and Zimbabwe. Needless to say, a comparison of such average costs should be approached with a degree of caution and are difficult to compare because of the variations in cost focus for each of the studies involved. The most important questions to ask with regard to all these out-of-pocket payments is, “How much did the patient pay?” and “Is such an average out-of-pocket payment in this rural setting affordable to the average patient?” In a population with a per capita expenditure on health of US\$ 18 and a Gross Domestic Product (GDP) of US\$ 243 (WHO 2005b:[1]), an average out-of-pocket payment per death of US\$ 11.3 represents a very high proportion of the per capita annual expenditure on health, and probably creates an obstacle that prevents patients who are suffering from severe and critical health conditions to access the emergency care that they require in good time.

When one links the conclusions at the researcher made in section 4.4.5.1 with regard to the high mortality rate that prevailed on the first day (24 hours) after admission, one may regard the cost of services per death as a confirmatory indicator that most patients only accessed hospital services very late in the course of their disease when no further options of health care were available to them. At this stage of illness, nearly all patients are critically ill and succumb to death in less than 24 hours after admission.

Because of the high prevalence of HIV in the region, patients should be encouraged to find out their HIV status as early as possible (certainly long before the symptoms of advanced disease have begun to appear), and should also be encouraged to commence treatment as early as possible so as to minimise the risk of severe illness that is associated with high costs and a high risk of mortality.

Total out-of-pocket payments were a good indicator of cost trends in the delivery of health services in the hospital. They are, however, estimates of costs that are based on the prevailing market prices of medical goods and supplies at the time, and they are unable to provide exact estimates of the actual daily cost of hospital services.

4.4.6.2 Average out-of-pocket payments in terms of gender

In order to understand the differences between out-of-pocket payments in terms of gender, the researcher carried out a further analysis on males and females separately. The purpose of a separate analysis of out-of-pocket payments made by females and males respectively was to determine whether there were any significant differences in out-of-pocket payments per death in terms of gender.

Table 4.11: The average out-of-pocket payments per death in terms of gender

Year	Female deaths (<i>n=190, missing-21</i>)			Male deaths (<i>n=305, missing-24</i>)		
	Average out-of-pocket payment per death (<i>in US\$</i>)(\pm SD)	Median out-of-pocket payment per death (<i>in US\$</i>)	Number of deaths reviewed <i>n</i>	Average out-of-pocket payment per death (<i>in US\$</i>)(\pm SD)	Median out-of-pocket payment per death (<i>in US\$</i>)	Number of deaths reviewed <i>n</i>
2002/2003	10.2 \pm 6.0	9.4	28	10.2 \pm 6.0	9.4	42
2003/2004	7.4 \pm 3.8	7.0	26	10.4 \pm 3.8	8.5	48
2004/2005	7.8 \pm 4.5	7.8	33	11.0 \pm 4.5	9.4	41
2005/2006	10.5 \pm 5.7	10.5	31	8.8 \pm 5.7	10.5	45
2006/2007	14.6 \pm 11.6	10.6	36	11.4 \pm 11.6	10.6	58
2007/2008	12.9 \pm 7.6	11.3	36	17.9 \pm 7.6	16.9	71
Average	10.6 \pm 6.6	9.4		11.6 \pm 6.6	10.9	

*SD-Standard Deviation

In the pre-free ART era, the average out-of-pocket payment per death for females was US\$ 8.5 (the average of US\$ 10.2, 7.4 and 7.8) compared to US\$ 12.7 (the average of US\$ 10.5, 14.6 and 12.9) in the post-free ART era. For males, the average out-of-pocket payment during the pre-free ART era was US\$ 10.5 (the average of US\$ 10.2, 10.4 and 11.0) compared to the US\$ 12.7 (the average of US\$ 8.8, 11.4 and 17.9) in the post-free ART era. This represented a 49.4% (US\$ 4.2) and 21% (US\$ 2.2) increase in out-of-pocket payments in the post-free ART era compared to the payments made by both the females and males respectively in the pre-free ART era. Table 4.11 shows that the average out-of-pocket payments for males and females in the three-year, post-free ART era out-of-pocket payments were equal at US\$ 12.7 per death event.

There was therefore no difference in the post-free ART era in the out-of-pocket payments in terms of gender. On average, the cost of death for each patient (male or female) was US\$ 12.7 in the post-free ART era.

4.4.6.3 Average out-of-pocket payments for HIV-related and non HIV-related deaths

HIV/AIDS and malaria were the most prevalent causes of death in the hospital (this is also described in section 4.5.3.1). Since this study focused on the effect of how access

to ART influenced mortality trends, the researcher undertook a further analysis of the out-of-pocket payments for HIV- and non-HIV-related deaths. He therefore analysed all out-of-pocket payments that were connected with all deaths after he had categorized them into HIV-related and non-HIV-related deaths.

Table 4.12: Out-of-pocket payments for HIV-related and Non HIV-related deaths

	HIV-related deaths (<i>n</i> =185, missing 14)			Non HIV-related (<i>n</i> =277, missing 23)		
	Average out-of-pocket payment for HIV-related deaths (\pm SD)	Exponentially Smoothed average out-of-pocket payment for HIV-related deaths	Number of deaths reviewed	Average Out-of-pocket payment for non HIV-related deaths (\pm SD)	Exponentially Smoothed average out-of-pocket payment for non HIV-related deaths	Number of deaths reviewed
2002/2003	9.5(3.9)	-	22	12(8.8)	-	32
2003/2004	9.1(4.5)	9.5	24	9.7(11.8)	12.0	48
2004/2005	10.7(5.9)	9.4	26	9.3(6.9)	11.5	41
2005/2006	10.7(5.1)	9.7	24	9.1(5.5)	11.1	46
2006/2007	11.4(5.4)	9.9	44	14(10.8)	10.7	49
2007/2008	15.5(11.5)	10.2	45	17.1(13.4)	11.4	61
Average	11.1(6)			11.9(9.5)		

In the six year period, the average out-of-pocket payment for HIV-related deaths was US\$ 11.1 in comparison to the US\$ 11.9 average out-of-pocket payments that patients had to make for non-HIV-related deaths.

4.4.6.4 Average out-of-pocket payment trends

By making use of the exponential smoothing technique with a dumping factor of 0.8 to minimize the effect of seasonality on average out-of-pocket payments, the researcher analysed trends and projections until June 2011. These are set out in figure 4.7 (below). The dumping factor of 0.8 ensured that the most recent trends that influence current post-free ART era trends were more heavily weighted in the determination of future trends.

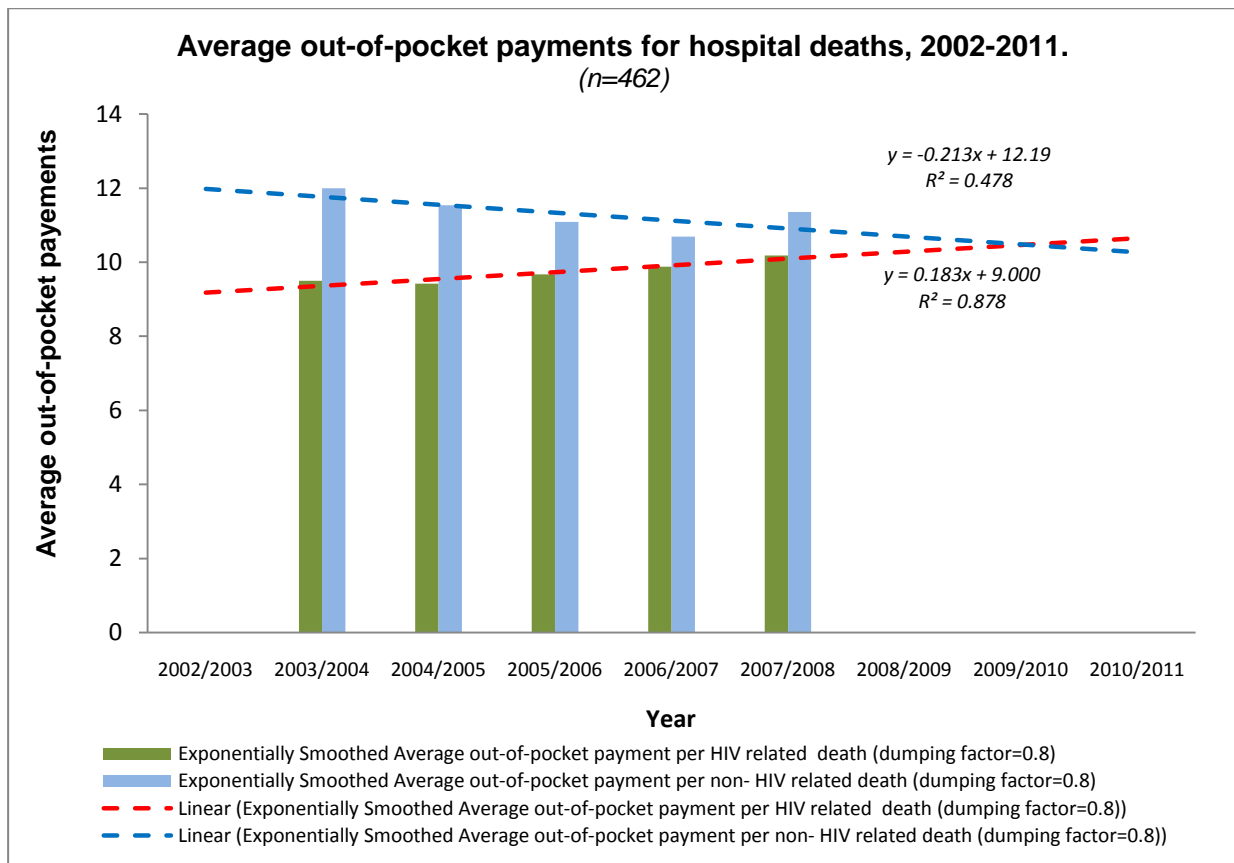


Figure 4.7: Average out-of-pocket payments for hospital deaths (2002-2011)

Figure 4.7 shows the average out-of-pocket payments and the projected costs as they will be in June 2011. These findings showed that, throughout the six-year study period (2002-2008), the average out-of-pocket payments for non-HIV-related deaths were higher than the average out-of-pocket payments for HIV-related deaths. But since the differences in average out-of-pocket payments were narrowing, the researcher projected that by the end of 2009/2010, the average cost for both HIV-related and non-HIV-related deaths would intercept (or equalise) at an estimated US\$ 10.5 per death. The research also projected that, by June 2011, the average cost for HIV-related deaths would exceed the cost of non-HIV-related deaths.

Non HIV-related out-of-pocket payments were declining at an estimated rate of US\$ 0.2 per annum ($y = -0.2x + 12.2$) from the US\$ 12 that they cost per death in 2002/2003, and they are projected to decline to US\$ 10.4 by June 2011. On the contrary, out-of-pocket payments for HIV-related deaths have increased at a rate of US\$ 0.2 per annum ($y = 0.2x + 9.0$) from US\$ 9.2, and are projected by the researcher to increase to US\$ 10.8 by June 2011.

The trends show that HIV-related costs are revealing a rising trend while non-HIV-related out-of-pocket payments are exhibiting a declining trend. The researcher projects that the average out-of-pocket payment for HIV-related illnesses will reach US\$ 10.8 per death in June 2011 in Uganda.

4.4.6.5 The daily out-of-pocket payments for hospital services

After he had analysed the average out-of-pocket payments made by patients, he also proceeded to analyse the daily out-of-pocket payments that patients made. Flessa (1998:404) reported an average daily fee per inpatient in a Tanzanian hospital at US\$ 1.5, with an average cost of health service delivery being kept within the sustainable limits of US\$ 6.4 per inpatient day. It is the cost of health services that determine whether or not patients can obtain timely access to available health services, and it is late access to such services that is associated with the extremely high morbidity and mortality rates that characterise the first 24 hours after admission to hospital (Yisa et al. 2004:53). It is because of the high cost of health services, that patients only consider the hospital as a completely last resort for care and treatment, and will exhaust all other options for health care (including traditional medicine and the services of herbalists and private clinics) before they can present themselves at the hospital.

Table 4.13: Daily out-of-pocket payment per death (2002-2008)

	Average daily out-of-pocket payment in US\$ (\pm SD)	Median daily out-of-pocket payment in US\$	Range (Minimum-Maximum) daily out-of-pocket payment in US\$	Number of deaths reviewed
2002/2003	3.1 \pm 2.6	2.5	0.1-14.9	60
2003/2004	3.0 \pm 2.5	2.3	0.3-16.0	65
2004/2005	4.1 \pm 4.9	2.9	0.2-27.8	56
2005/2006	3.5 \pm 2.5	2.8	0.2-10.5	58
2006/2007	4.0 \pm 4.1	2.7	0.4-29.7	79
2007/2008	6.0 \pm 7.7	3.5	0.1-54.1	85
Average	3.9 \pm 4.0	2.8	0.2-25.5	403

(n=403, missing 141)

The average daily out-of-pocket payments that patients made increased from US\$ 3 in 2003/2004 to their most recent high point of US\$ 6 in 2007/2008. Although the median daily out-of-pocket payments made by patients as a measure of central tendency was less sensitive to outlier values, these payments increased by 40% (US\$ 1) from US\$ 2.5 to US\$ 3.5 over a six-year period. In order to analyse these trends, the researcher

exponentially smoothed the average daily out-of-pocket payments with a dumping factor of 0.8, and the findings are presented in figure 4.8 below.

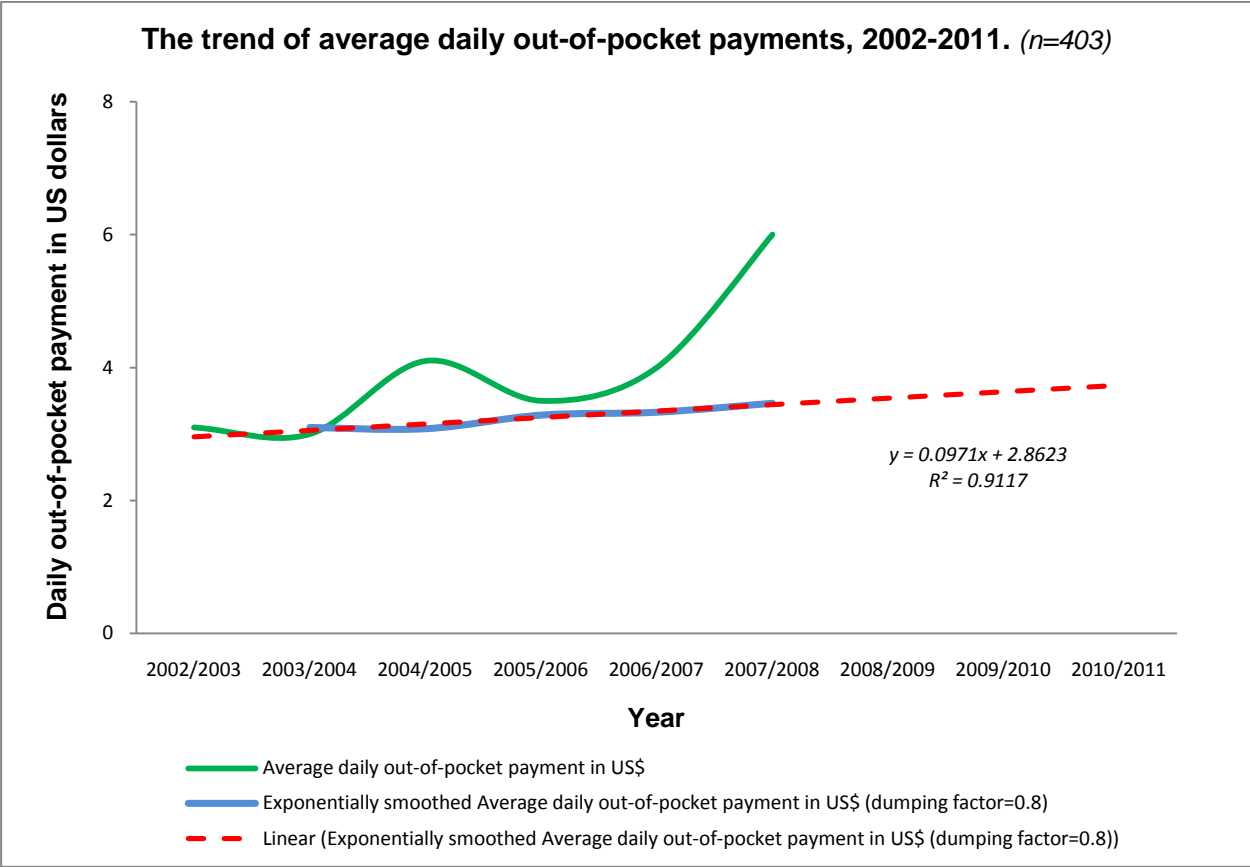


Figure 4.8: The trend of average daily out-of-pocket payments (2002-2011)

The data presented in figure 4.8 show a slow increase in the daily out-of-pocket payments that patients made. With 2002/2003 as the index year, these daily out-of-pocket payments increased by US\$ 0.1 annually ($y = 0.1x + 2.9$). The researcher therefore projected that, by June 2011, the daily out-of-pocket payments would be US\$ 3.7 per death.

The median daily out-of-pocket payment of US\$ 3.5 (in 2007/2008) was therefore twice the earlier reported out-of-pocket payments for inpatients in a similar setting in Tanzania even though it was below the average cost of a sustainable service delivery.

Table 4.14: The daily out-of-pocket payments per death in terms of gender

	Female deaths (<i>n</i> =161, <i>missing</i> -50)			Male deaths (<i>n</i> =239, <i>missing</i> -90)		
	Average daily out-of-pocket payment in US\$ (\pm SD)	Median daily out-of-pocket payment in US\$	Number of deaths reviewed	Average daily out-of-pocket payment in US\$ (\pm SD)	Median daily out-of-pocket payment in US\$	Number of deaths reviewed
2002/2003	2.8 \pm 2.0	2.4	27	3.3 \pm 3.0	2.5	32
2003/2004	2.9 \pm 2.2	2.4	22	3.0 \pm 2.6	2.3	43
2004/2005	3.6 \pm 3.8	1.9	25	4.5 \pm 5.6	3.1	31
2005/2006	3.6 \pm 2.2	3.3	25	3.4 \pm 2.7	2.6	33
2006/2007	4.0 \pm 3.4	3.2	33	4.0 \pm 4.6	2.7	45
2007/2008	4.4 \pm 3.7	3.2	29	6.8 \pm 9.2	3.8	55
Average	3.5 \pm 2.9	2.7		4.2 \pm 4.6	2.8	

Because the median is a more reliable measure of variables with wide dispersion, the researcher used the median daily out-of-pocket payment in order to carry out an analysis of changes in out-of-pocket payments. For females, the out-of-pocket payments increased by 33.3% from US\$ 2.4 (2002/2003) to US\$ 3.2 (2007/2008). Among males, comparable out-of-pocket payments increased by 52.0% from US\$ 2.5 (2002/2003) to US\$ 3.8 (2007/2008). Although table 4.14 indicates that the daily out-of-pocket payments for both males and females increased during these periods, the increase in daily out-of-pocket payments for males was higher than that for females. These findings indicated that male admissions and deaths were significant cost drivers in overall out-of-pocket payments.

Despite free access to ART in this high HIV prevalence setting, the average direct out-of-pocket payment on the part of patients for health care increased by 33.3% to 52.0% over a six-year period. Such a dramatic increase in out-of-pocket payments in a private-not-for-profit hospital makes it evident that the cost of service delivery per mortality to the hospital and to the patients during the period under consideration increased sharply and revealed a rising trend.

4.4.7 The associations between length of stay, out-of-pocket payments and HIV

Apart from the out-of-pocket payments the researcher evaluated in this study, the cost of services and problems connected with the fixing of out-of-pocket payments were beyond the scope of this study. Other aspects including the maintenance of a reliable and constant supply of sufficient ARV medicines to the hospital and various other barriers that prevented effective access to ART, were also beyond the scope of this study. But in this section, the researcher summarises the findings of the relationship between HIV-related mortality and patient length of stay in hospital before death, and correlates these factors with an increase in ART coverage in Mawokota South Health sub-District.

4.4.7.1 Average length of stay and post-free ART era out-of-pocket payments

Any illness that results in death is considered serious. However, in order to facilitate the discussion on the association between the degree of severity of illness before death and the out-of-pocket payments, the researcher categorised deaths objectively by using the average number of days the patient spent in the hospital after admission before death, and categorised deaths by degree of severity at the time of admission. The number of days before death was thus an indicator of the diagnosed or undiagnosed degree of severity of the illness on admission.

Deaths that occurred in less than one day of admission were considered to be ‘very serious (critical) illnesses’ by the time of admission. Deaths that occurred in two to three days of admission were considered to be ‘moderately serious illnesses’ on admission, while deaths that occurred after three days of admission were considered to be ‘mild but serious illnesses’ on admission that lead to death. Deaths were therefore categorised into: (a) deaths that occurred within three days of admission or less, and (b) deaths that occurred after three days of admission. In this study, analysis of 404 deaths showed that the average daily out-of-pocket payment was US\$ 4 per patient. By using the average daily out-of-pocket payment of US\$ 4 per death, the researcher categorised out-of-pocket payments into the following two categories: (a) death events for which a patient paid US\$ 4 or less, and (b) death events for which the patient paid more than US\$ 4 (above average) as an out-of-pocket payment per day. The cut-off point of US\$ 4 per day of admission or less as the amount of money that is expended on direct health

care in the hospital was considered to be average, while an amount of more than US\$ 4 per day of admission was considered to be above average.

Table 4.15: Average length of stay in hospital and out-of-pocket payments

Number of admission days	Daily out-of-pocket payment in US\$		TOTAL number of deaths <i>n (%)</i>
	Equal to or less than US\$ 4 <i>n (%)</i>	More than US\$ 4 <i>n (%)</i>	
≤3 days of admission	102(49.3) (36.7)	105(50.7) (91.3)	207 (52.7)
>3 days of admission	176(94.6) (63.3)	10(5.4) (8.7)	186 (47.3)
TOTAL	278(70.7)	115(29.3)	393

(n=393, missing-151)

The researcher detected a statistically significant association between the number of admission days that patients spent in the hospital and the out-of-pocket payments that the patient made ($\chi^2=97.2$, $p<0.0001$), in a context in which 91.3% ($n=115$) of all patients who paid out-of-pocket payments of more than US\$ 4 died within three days of admission.

There was therefore a higher probability that patients who died within three days of admission to the hospital would pay more than US\$ 4 in out-of-pocket payments compared to those who remained in hospital for more than three days after they had been admitted (OR=0.06, 95% CI[0.03-0.11]). This finding once again confirmed the severity of the illnesses and conditions with which patients presented that resulted in death within three days of admission to the hospital. This may have been caused by the fact that the management and care of patients who were admitted with serious illnesses and conditions that resulted in death in fewer than three days after admission, required more expensive investigations as well as more medications and treatments.

4.4.7.2 Association between HIV mortality and out-of-pocket payments

The research analysed the relationship between HIV-related mortality and the out-of-pocket payments that patients made for the care that they received in the hospital. Since HIV/AIDS-related deaths are a major cost driver in the hospital, this analysis

offered some insight into what was the cost of HIV-related mortality is in relationship to the cost of non-HIV-related mortality.

Table 4.16: The association between deaths and daily out-of-pocket payments

HIV-related deaths	Average daily out-of-pocket payment (US \$)		Total n (%)
	Less than US\$ 4 n (%)	More than US\$ 4 n (%)	
Yes	115(72.8) (44.2)	43(27.2) (38.1)	158 (42.4)
No (Other deaths)	145(67.4) (55.8)	70(32.6) (61.9)	215 (57.6)
Total	260(69.7)	113(30.3)	373

(n=373, missing-171)

In table 4.16, 72.8% (n=158) of the patients who died from HIV-related causes paid less than US\$ 4 per day compared to the 67.4% (n=215) of patients who died from non-HIV-related causes. But this difference was not statistically significant ($\chi^2=0.99$; $p=0.32$; OR=1.29 [0.82-2.03]).

The odds of a patient having to pay US\$ 4 or less as an out-of-pocket payment were similar for those who died from both HIV-related and non-HIV-related causes. Thus the HIV status of the patient did not in fact increase or reduce the risk of having to pay more or less than US\$ 4 as an out-of-pocket payment per admission day in hospital before death intervened.

4.5 THE EFFECT OF ANTIRETROVIRAL TREATMENT ON MORTALITY

Since HIV/AIDS exerts a significant and fundamental socio-economic impact on all communities in which it is highly prevalent. The health systems and the overall development patterns in countries experience an enormous effect due to HIV/AIDS. The fundamentally destructive impact of HIV on morbidity and mortality trends cannot be sufficiently overemphasized. In East and Central Africa, rates of adult mortality substantially increased because of the high prevalence of HIV. This in itself indicates that mortality trends in the region have been fundamentally driven by patterns of HIV

prevalence (McMichael et al. 2004:1156). Since one third of all adult deaths in Uganda were HIV-related by 2005, HIV/AIDS was already the leading cause death at that time (Hladika et al. 2008:509).

In this section, the researcher examines hospital morbidity and mortality trends, and presents and discusses the results that he obtained below.

4.5.1 Antiretroviral therapy and the risk of disease progression

Since the way in which HIV infection progresses to an advanced stage of morbidity (AIDS) as a determinant of mortality was beyond the scope of this study, references to this factor were included in the literature review but have not been included in this section of the overall analysis.

4.5.2 Hospital morbidity and mortality trends

Since antiretroviral medicines forestall the multiplication of the HIV and reduce the risk of disease progression, they serve to reduce HIV-related morbidity and mortality. Studies have reported that the reasons for admission to the hospital have changed over the years, with opportunistic infections now cited as the reason for proportionately fewer admissions. In this study, the researcher evaluated morbidity patterns by means of an analysis of adult admission trends.

Hospital morbidity and mortality trends exert a significant impact on the workload that a hospital has to sustain and the cost of service delivery. Since the overall goal of free access to ART was to reduce the incidence of morbidity and mortality trends among HIV-affected patients, the researcher compiled data about admission and mortality trends and analysed these in an attempt to answer various questions. Because of the seasonal variations in admissions and mortality, the researcher was able to project overall trends and make future projections by using the technique of exponential smoothing with a dumping factor of 0.95. This approach ensured that the most recent admission and mortality data that was influenced by the effects of ART coverage and other more recent socio-economic factors were more heavily weighted than older data and this provided a basis for more realistic and accurate future projections.

This study did not concern itself primarily with the mortality rates of HIV patients or patients who were participating in ART programmes. It was rather concerned with an overall examination of the morbidity and mortality trends in the pre-free and post-free ART eras in terms of the number of admissions, the causes of death, the number of deaths that occurred, and the hospital's overall mortality rate. There for mortality patterns among patients accessing free ART were not the focus of this discussion.

4.5.2.1 Adult admission trends in Mawokota South health sub-district

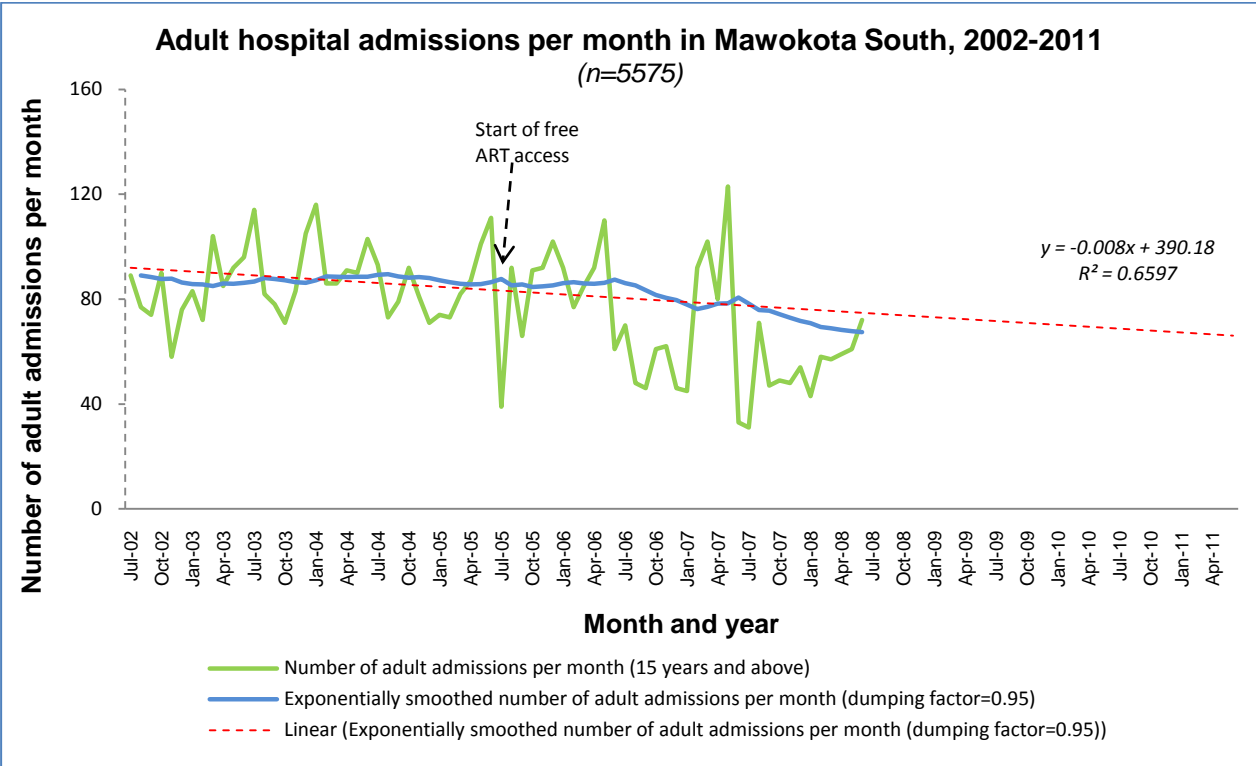


Figure 4.9: Adult hospital admissions per month in Mawokota South (2002-2011)

The researcher's review of the monthly admission trends of 5 575 adult patients over a 72-month (six year) period showed that adult admissions in the hospital decreased by 16.7% from an average of 90 admissions per month in July 2002 to 75 admissions per month in June 2008. He also projected that hospital admissions would drop to 65 admissions per month by June 2011. By June 2011, mortality trends will have been reduced by 27.8% of the 2002/2003 monthly adult admission average.

Similar findings by other researchers (Beck et al. 1999:2160; Carter 2005:[1]; Kumar et al. 2000:[1]; Smart 2008:[1]) have indicated that free ART access has contributed the 16.7% reduction in adult monthly hospital admissions. The researcher also projected that, in the near future (subject to similar conditions in hospitals and in the population) the number of adult admissions was on a declining trend. The projections about hospital admission rates should however, be taken with a pinch of salt because this trend may be masked by other factors that influence access to hospital services for example out-of-pocket payments that were analysed in the earlier part of this study or by factors that are beyond the scope of this study.

4.5.2.2 Adult mortality trends in Mawokota South health sub-district

After the analysis of adult admission trends that were available from the hospital's records, the researcher also analysed the trends observed in the number of adult deaths per month. He applied an exponentially smoothed trend with a dumping factor of 0.95 signifying the importance of the recent increased access ART as a key determinant of current and future mortality patterns and presented the results below in figure 4.10 (below).

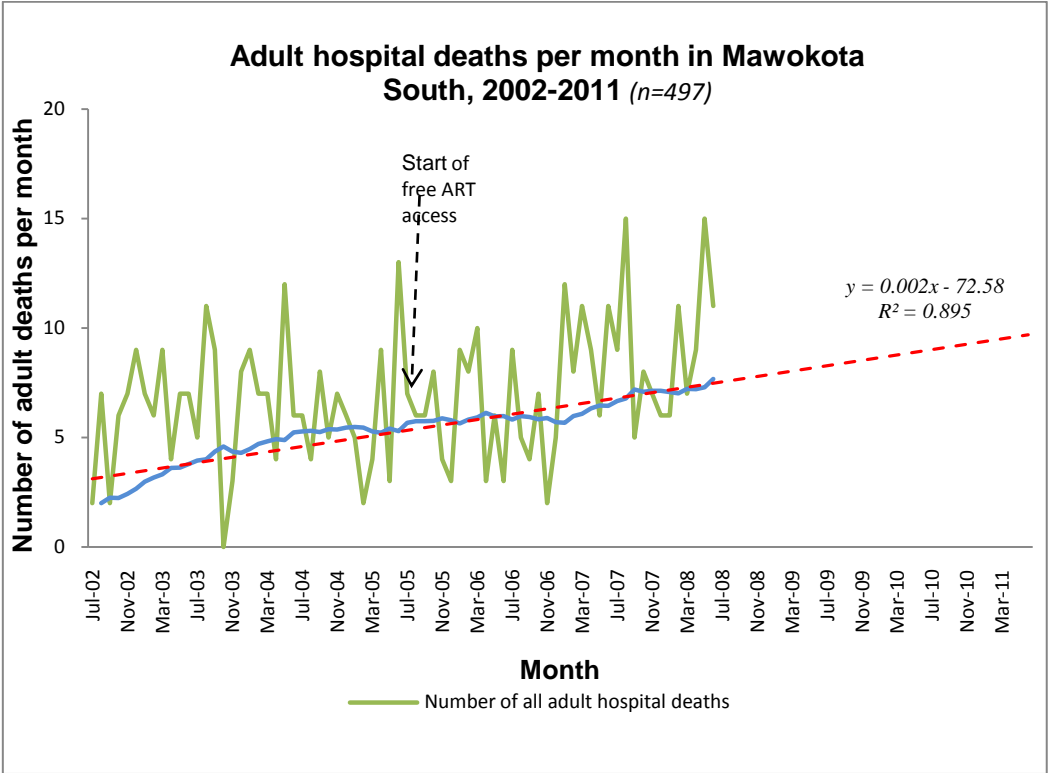


Figure 4.10: Adult hospital deaths per month in Mawokota South (2002-2011)
203

Four hundred and ninety seven (497) deaths were reviewed by the researcher. Figure 4.10 shows that adult deaths increased by 133.3% from an average of three deaths per month in July 2002 to seven deaths per month in June 2008. This rate of mortality was projected to continue to increase, and by June 2011, the researcher expected the hospital mortality rate to increase to ten deaths per month. This increase in mortality rates from three deaths per month in 2002/2003 to a projected ten deaths per month in June 2011 will represent a 233.3% increase in the monthly average of hospital deaths.

This increasing number of hospital deaths that are occurring in a rural hospital setting in Uganda run contrary to the findings in other studies that have reported a reduction in HIV/AIDS mortality and overall mortality rates as ever greater numbers of the population gain access to ART (Carter 2005:[2]; Gomez et al 2004:[1], Jahn et al. 2008:1607; Thaczuk & Differding 2008:[2]; United Nations 2008:28).

In the post-free ART era, the number of adult hospital deaths per month increased and was projected by the researcher to reach on average of ten deaths per month in June 2011. What is evident from the data is that free access to ART in Mawokota South health sub-district over a three-year period did not reduce hospital mortality rates (i.e. the number of patient deaths that occur each month).

This rising mortality trend together with reductions in the morbidity trends could be ascribed to the initial positive impact that ART makes on morbidity trends and minimal impact that it makes on mortality trends. This increase in mortality trends could also be ascribed to the limited targeting of interventions and the limited access to ART to PLWHA with the highest risk of mortality due to HIV related illness (high risk groups).

4.5.2.3 Mortality trends in Nkozi sub-county in Mawokota South Country

Despite the increase in the rates of hospital mortality during the period under study, figure 4.3 indicates that Nkozi sub-county showed an 8.7% (n=183) *reduction* in hospital deaths. This is a finding that requires a further analysis of the mortality trends in this sub-county.

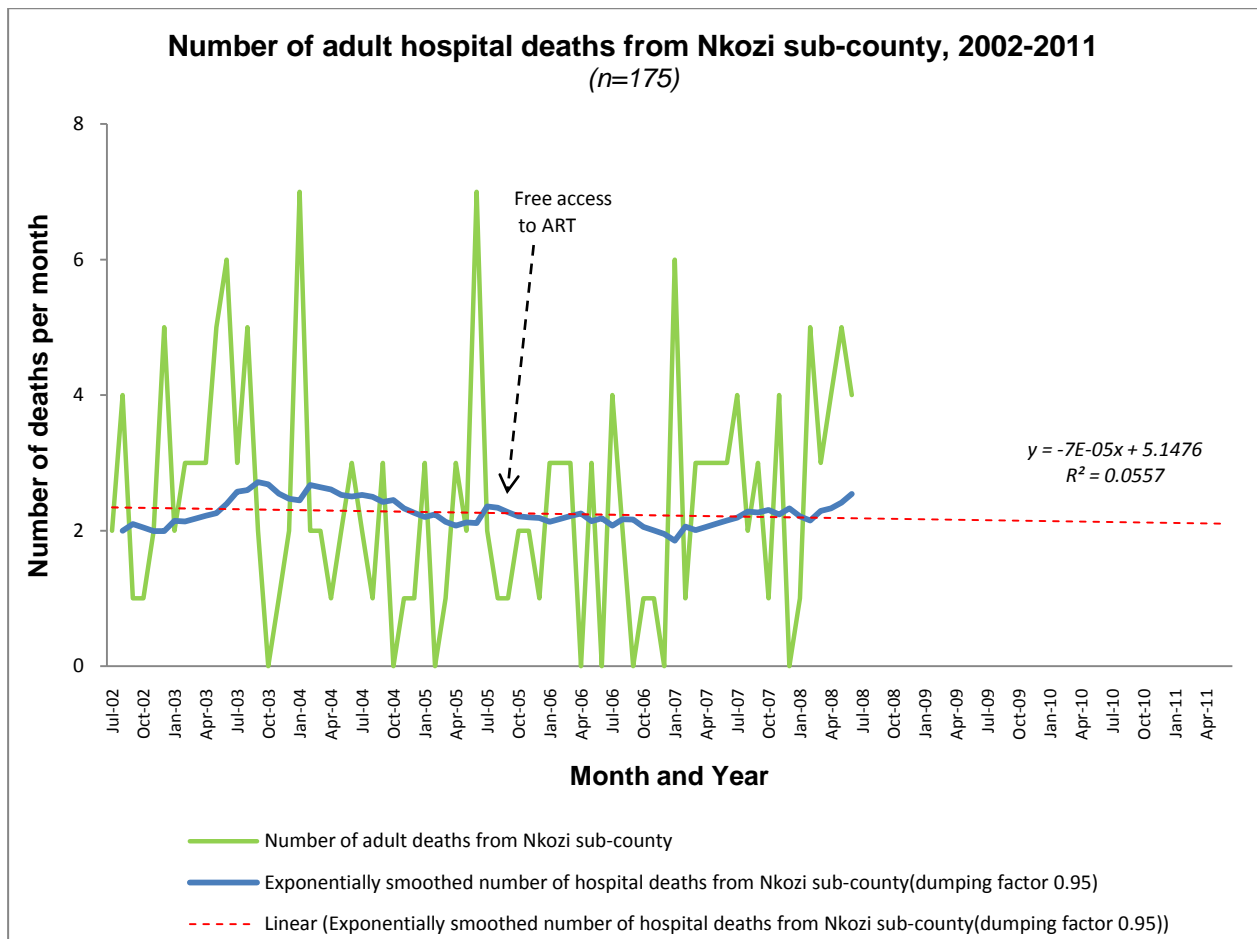


Figure 4.11: Number of adult hospital deaths from Nkozi sub-county (2002-2011)

Figure 4.11 shows that the number of hospital deaths in the sub-county in which the hospital under study was located (a sub-county which ART was introduced in June 2005) showed a downward trend. Despite the overall increase in hospital mortality from three deaths per month to seven deaths per month (see figure 4.10), the number of deaths that occurred in the Nkozi sub-county showed a decline from 2.4 deaths per month (in July 2002) to 2.2 deaths per month in (in June 2008), and the researcher projects that this rate will be reduced to 2.1 deaths per month in June 2011. Although this is a marginal decline in the monthly mortality in from Nkozi sub-county, this marginal decline is significant and worth monitoring in the context of the increasing overall mortality rate.

It seems that this decline in number of hospital deaths from Nkozi sub-county indicates one of the initial effects of increased access to free ART in the sub-county and its effect on the overall hospital mortality trends. All the other factors that might have determined

this reduction in the rate of hospital deaths for Nkozi residents were beyond the scope of this study.

4.5.2.4 Association between length of stay and HIV-related mortality

The researcher investigated the association between the average length of hospital stay in the pre-free and post-free ART eras and making use of the median length of hospital stay. The patient deaths were categorized according to the average length of stay that the patient had spent in hospital – whether a period of three admission days and less or a period of more than three admission days.

As highlighted earlier, the number of admission days before death was indicative of the severity of illness presented with on admission. Deaths that occurred within three days of admission were considered to be the most serious and critical illness. This analysis enabled the researcher to determine whether there had been a difference in the severity of illness patients presented with on admission, indicated by proportion of deaths that occurred within less than three days of admission days in both the pre-free and post-free ART eras.

Table 4.17: The association between length of hospital stay and treatment era

Treatment Era	Length of hospital stay before death		TOTAL number of deaths n(%)
	≤3 days of admission n(%)	>3 days of admission n(%)	
Post-free ART	154(57.9) (53.1)	112(42.1) (56.0)	266 (54.3)
Pre-free ART	136(60.7) (46.9)	88(39.3) (44.0)	224 (45.7)
TOTAL	290(59.2)	200(40.8)	490

(n=490, missing 54)

The results of the analysis of 490 pre-free and post-free ART deaths showed that, in the post-free ART era, 57.9% (n=266) of the patients died within three days of admission compared to the 60.7% (n=224) of patients who died within the same period in the pre-free ART era. This difference was not statistically significant (OR=0.89, 95% CI [0.62-1.28]; $\chi^2=0.3$; p=0.59) since the risk of death intervening within three days of admission

was similar for patients who admitted in both the pre-free and post-free ART eras, therefore one can conclude that free ART access among other factors had not significantly affected the severity of illness which patients presented on admission. Therefore, using number of days of admissions before death as an indicator of the severity of illness patients presented with, patients continue to present with serious illness with no significant difference in this before between the pre-free and post-free ART eras.

If one therefore compares the mortality rate of patients who were admitted in the post-free ART with that of patients who admitted in the pre-free ART era, no change was detectable in the proportion of patients who were admitted with serious or critical illnesses and conditions that resulted in their death within three days of admission. Since most of the patients were accessing health care with advanced symptoms of disease, a significant proportion (59.2%, n=490) of all deaths among such patients occurred within three days of admission to the hospital.

With a significant proportion of patients presenting with serious and critical illness, it is evident that there is minimal possibility of reducing mortality patterns. With this scenario, hospital mortality rates can only stagnate or increase. This confirms the findings of increasing hospital mortality rates, despite increased access to free ART.

Table 4.18: Association between HIV related mortality and hospital stay for females

HIV related death	Length of Hospital stay before death		TOTAL number of deaths n (%)
	Equal to or less than 3 days of admission n (%)	More than 3 days of admission after n (%)	
Yes	37(47.4) (37.4)	41(52.6) (49.4)	78 (42.9)
No	62(59.6) (62.6)	42(40.4) (50.6)	104 (57.1)
TOTAL	99(54.4)	83(45.6)	182

(n=182, missing-29)

Table 4.18 above shows that 37.4% (n=99) of all the female deaths that occurred within three days of admission were due to HIV-related causes in comparison to the 49.4% (n=83) of deaths that occurred within more than three days of admission. The difference

in the likelihood (risk) of HIV-related deaths for females within less than three days of admission and in more than three days of admission was not statistically significant ($\chi^2=2.20$; $p=0.14$; $OR=0.61$, 95% $CI[0.33-1.13]$). However, the relative risk of HIV-related death within less than three days after admission was less by 20.4% (95% $CI[-4.6\%-40.1\%]$) when compared to the number of deaths that occurred within more than three days after admission.

Female HIV-related and non-HIV-related deaths were therefore equally likely to be admitted with severe or critical illnesses and conditions that resulted in their death within less than three days after admission to the hospital.

Table 4.19: Association between HIV-related mortality and hospital stay for males

HIV-related death	Length of hospital stay before death		TOTAL <i>n (%)</i>
	≤ 3 days of admission <i>n (%)</i>	> 3 days of admission <i>n (%)</i>	
Yes	50(50.0) (31.6)	50(50.0) (46.7)	100 (37.7)
No	108(65.5) (68.4)	57(34.5) (53.3)	165 (62.3)
TOTAL	158(59.6)	107(40.4)	265

(n=265, missing-64)

Table 4.19 shows that 50% ($n=100$) of male HIV-related deaths occurred within three days of admission compared to 65.5% ($n=165$) of non-HIV-related deaths. This difference was statistically significant ($\chi^2=5.55$; $p=0.02$). Therefore, the odds that a male patient would die from IV-related death occurred within three days of admission were 0.53 (95% $CI [0.32-0.88]$). Male HIV-related deaths were less likely to occur within three days of admission to the hospital.

Therefore, compared to females, male HIV-related deaths occurred in more than three days of admission. Female HIV-related and non HIV-related had equal likelihood of occurring in less than three days and after three days of admission.

4.5.3 The effect of antiretroviral therapy on mortality trends

Since ART became increasingly available to the Ugandan population, the reasons why people are hospitalised and the causes of death among HIV-positive patients are changing and therefore need to be carefully monitored. In Uganda, HIV/AIDS has significantly affected morbidity and mortality trends and remains the major single most urgent challenge to the delivery of health services. In 2003 to 2004, it was estimated that HIV/AIDS caused 25% of all deaths among people of all ages in Uganda (WHO 2004a:2).

This section summarised the causes of mortality in the pre-free ART era and compared those causes with the causes of mortality in the post-free ART era. In this section, the researcher also analysed and discussed the impact of ART on the overall ("all causes") reasons for death since the introduction of free ARVs.

4.5.3.1 The effect of antiretroviral therapy on the causes of mortality

The determination of the causes of death was a key focus of this study. By making use of the diagnoses in the patients' hospital records, the researcher was able to compile a list of all the causes of death listed in the pre-free ART era and in the post-free ART era for the time period covered by this study. This section focuses on the frequency distribution of the causes of death (since each patient could have died from more than one cause of death). As a result of this investigation, the researcher discovered that the average number of causes of death for each patient who died was 1.7 in the pre-free ART era and 1.6 in the post-free ART era.

Table 4.20: Causes of death in the pre-free and post-free ART eras (2002-2008)

	Pre-free ART causes of death <i>n (%)</i>	Post-free ART causes of death <i>n (%)</i>	Percentage of causes of death <i>n (%)</i>	Percentage change in the post-free ART era (%)
Tuberculosis	37(12.8)	29(6.6)	66(9)	-6.2
Cardiovascular causes [‡]	26(9)	22(5)	48(6.6)	-4.0
Meningitis	16(5.5)	13(2.9)	29(4)	-2.6
Respiratory causes (RTI [†])	34(11.7)	39(8.8)	73(10)	-2.9
Malignancies	6(2.1)	3(0.7)	9(1.2)	-1.4
Anaemia	11(3.8)	20(4.5)	31(4.2)	0.7
Other Causes	15(5.2)	28(6.3)	43(5.9)	1.1
Other GIT* conditions	6(2.1)	13(2.9)	19(2.6)	0.8
Diabetes mellitus	2(0.7)	6(1.4)	8(1.1)	0.7
Renal conditions	1(0.3)	8(1.8)	9(1.2)	1.5
Gastro enteritis	8(2.7)	25(5.6)	33(4.5)	2.9
HIV/AIDS	80(27.6)	119(26.9)	199(27.1)	-0.7
Malaria	48(16.5)	118(26.6)	166(22.6)	10.1
Total	290	443	733	

(*n*=733)

[‡] While cardiovascular causes included cerebral vascular accident, hypertension and heart failure, but excluded anaemia.

[†] RTI – Respiratory tract infections.

* GIT – Gastro intestinal tract. Other GIT conditions included peptic ulcer disease and intestinal obstruction.

Table 4.20 indicates that HIV/AIDS was the most prevalent cause or associated cause of death and that it was responsible for 27.1% (*n*=733) of all the deaths in the hospital. The second most common cause of death was malaria, which was responsible for 22.6% (*n*=733) of all deaths. The third most common cause of death was respiratory tract infections (RTI) 10% (*n*=733), while tuberculosis (TB) was responsible for 9% (*n*=733) of all hospital deaths in the period covered by this study.

The number of deaths that were caused by TB in the hospital was very similar to the number of deaths that were caused by TB in a study in Zambia, which reported that TB caused 7% of all the deaths that were investigated in that study (Kelly et al. 1998:883). With regard to HIV/AIDS as a cause of mortality, the findings in this study reported similar findings to the WHO report of HIV contributing to 25% of all deaths in Uganda (WHO 2004a:2). But in two previous studies that were conducted in Northern Uganda, the researchers had showed that HIV/AIDS-related factors had been determined as the cause of death among 11.5% and 20.2% of the deaths (Accorsi, Fabiani, Lukwiya,

Onek, Di Mattei & Declich for the Italian-Ugandan AIDS cooperation program 2001:157; Fabiani, Accorsi, Aleni, Rizzardini, Nattabi, Gabrielli, Opira & Declich for the Italian-Ugandan AIDS cooperation program 2003:65).

In the Lacor study, TB had been the cause of death for 17.2% of the sample (compared to 9% in this study), respiratory tract infections had been the cause of death for 11.8% of the sample (as opposed to 10% in this study), and gastro-enteritis had been the cause of death for 4.4% of the sample (as opposed to the cause of death for 2.9% in this study) (Fabiani et al. 2003:65). There were differences in the findings about the extent to which malaria was a cause of death. The Lacor study reported malaria as a cause of death in only 2.2% of the sample (as opposed to the 22.6% who identified as having died from malaria in this study). Malaria and lower respiratory tract infections contribute 11% each to the overall mortality rate (WHO 2004a:2).

The key limitation of this study was incomplete and sometimes fragmentary state of the mortality records that were available to the researcher for analysis. Eight percent (8.3%, n=544) of the study population had been assigned no recorded direct or associated cause of death. Secondly, while 27.6% (n=544) of the deaths of patients who were at risk of HIV because of their age profile, these records had no record on their HIV status.

An analysis of the records show that HIV/AIDS, malaria and RTIs were the most widespread causes of death, and that they accounted for 59.7% (n=733) of the deaths that occurred in the hospital. A study conducted by the WHO, on the other hand, reported a mortality rate due to these three conditions (namely, HIV/AIDS, malaria and RTIs) of only 47% of all recorded deaths (WHO 2004a:2; WHO 2006b:2). In this study, HIV/AIDS and malaria were reported as being a direct or associated cause of death in 49.8% (n=733) of the deaths.

Therefore, in this rural hospital setting, the frequency of HIV/AIDS, malaria, respiratory tract infections and TB as causes of mortality were comparable in frequencies with the causes of death in Uganda reported in other studies. HIV/AIDS was the leading cause of death followed by malaria.

The findings that were set out in table 4.20 are presented in figure 4.12 (below) so that changes in the frequency of causes of death are more easily visible. These findings will be discussed and analysed below.

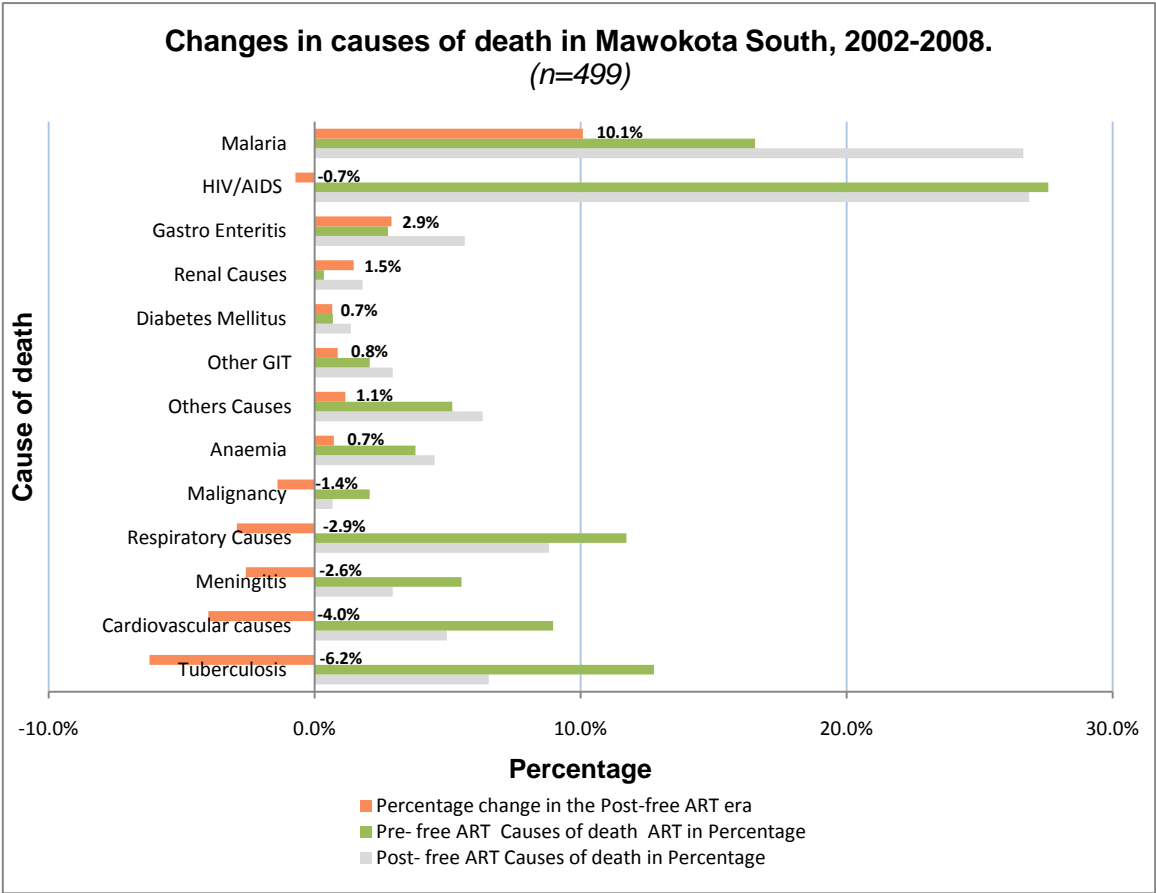


Figure 4.12: Changes in causes of death in Mawokota South (2002-2008)

The burden of HIV/AIDS in a 1999 hospital sero-survey reported that more than 52.6% of the patients in the medical wards in northern Uganda were HIV-positive, and that HIV disease was contributing to enormous overcrowding in out-patients departments (Fabiani et al. 2003:63-4). Figure 4.12 shows that the frequency of HIV/AIDS as a cause of death was reduced by 0.7% (n=199) in the post-free ART era compared to the pre-free ART era, that malaria as a cause of death increased by 10.1% (n=166), and that gastro-enteritis increased by 2.9% (n=33) as a cause of death in the same period. By contrast, tuberculosis as a cause of death reduced by 6.2% (n=66) and cardiovascular causes and meningitis reduced by 4% (n=48) and 2.6% (n=29) respectively as causes of death in the same period.

This slight reduction of 0.7% in the prevalence of HIV/AIDS as a cause of death requires further study (research) especially in view of the fact that 27.6% (n=544) of the deaths in the hospital did not have a confirmed or documented HIV status. The absence of any post mortem diagnosis in so many cases is a factor that limits research into accurate diagnoses of the cause(s) of death. The initial findings with regard to the reduction in HIV/AIDS-related deaths show that this reduction was low and not statistically significant ($\chi^2=0.39$; $p=0.53$: see table 4.20), but they are indicative of a trend that needs to be carefully monitored and analysed. Since free access to ART had only been available in the previous three years, this represented a period that was too short for making meaningful measurements about the impact of ART. But more long-term studies (such as, for example, a 14-year period study), would show that the AIDS-related causes of death (when compared to non-HIV-related causes of death) had decreased by 80% between the post-ART and the pre-ART eras (Crum et al. 2006:195).

The opportunistic infections that the researcher included in this analysis were TB, gastro-enteritis and meningitis. During the post-free ART era, there was a 6.2% reduction in the incidence of deaths caused by pulmonary tuberculosis, a 2.9% reduction in the incidence of deaths caused by meningitis, and an increase of 2.9% in the incidence of deaths caused by gastro-enteritis. Another researcher has reported an increase of the rate of TB infections in the Mpigi district that he attributed to the influence of HIV/AIDS-related factors (Miti 2008:[1]). The present study showed that TB as a cause of death declined by 6.2% during the period in which the study was undertaken. But this finding is at variance with the number of reports that indicate an increase in the number of TB cases. This discrepancy may imply challenges that the professional staffs of the hospital are having in diagnosing TB as a cause of death. The low and decreasing percentage of TB deaths reported by the present study may be associated with various challenges in the timely diagnosis of TB, and may also be attributable to a number of TB cases that have been missed and reported as RTIs. It is also interesting to note that Thaczuk and Differding (2008:[2]) reported that deaths attributable to HIV/AIDS and tuberculosis fell from 22 and 23 per 1 000 person-years in women and men respectively in 2003/2004 (pre-ART), to a level of 16 among women and 18 among men in 2005/2006 respectively after the introduction of ART.

The hospital in which the research was conducted did not have an X-ray machine for five out of six years of the study period. Any diagnosis of TB would therefore have to

depend upon a clinical and laboratory (sputum) evaluation. Because 59.2% (see section 4.4.5.1) of the patients died within three days of admission to the hospital, it is more than probable that, by the time of their death, diagnostic investigations would have been incomplete to either confirm or eliminate the presence of TB as a cause of death. It is therefore very likely that TB as a cause of death was widely under-diagnosed and under-reported.

The results of the present study show that the prevalence of malaria as a cause of death increased by 10.1% (n=166) in the post-free ART era. The increase in reported deaths caused by malaria may be indicative of the following two situations that are described below:

1. There might well have been an increase in the incidence of malaria as a cause of death in the community in the post-free ART era. A synergy between HIV and malaria has been reported in various studies. In a study undertaken in the Lacor Hospital in Northern Uganda, the prevalence of HIV among malaria in-patients was 52.2% in 1999 (Fabiani et al. 2003:65). This implies that there is a very high possibility that the increase in mortality due to malaria can be associated with the high incidence of HIV-related conditions among admitted patients.
2. Because of the limited diagnostic capacity of a hospital during the period of study, the reported increase in malaria could be attributed to an absence of any confirmable cause of death for the purposes of post-mortem reports. It is therefore likely that a number of fever-related causes of death were simply diagnosed as deaths caused by malaria, without any further investigation. If this were the case, the data in the hospital records would indicate a false increase in malaria-related mortality.

Similar findings were reported in the study conducted by Crum et al. (2006:195). They found that opportunistic infections such as tuberculosis and meningitis as a causes of death were less frequently reported in the post ART era compared to the pre ART era. On the other hand, malaria and gastroenteritis were more frequently reported as a cause of death in the in the post-free ART era. The implications of these findings suggest that the impact of ART on the incidence of opportunistic infections need carefully monitoring. None of these figures should be taken at face value and all the

proximate and peripheral causes of death in these settings need careful and continuous evaluation.

This study found that the causes of death in this period of research were frequently based on inadequate confirmation of causes of death. Therefore, the mortality trends due to conditions such as lymphomas, malignancies and other non-HIV-related causes of death are undoubtedly also inadequately reported.

But the key findings of this analysis were that there has been an increase in malaria and gastro-enteritis as causes of death and a reduction in tuberculosis and meningitis as causes of death in the post-free ART era as compared to the pre-free ART era.

4.5.3.2 Antiretroviral treatment coverage in Mawokota South (2002-2008)

In Mawokota South health sub-district, which was the focus of this study, ART coverage was estimated at 60% coverage of 29.2% of PLWHA (see figure 4.14). This extent of coverage in Mawokota South health sub-district was higher than the national average coverage of ART, which was reported as being 50.2% at the end of 2008 (Ministry of Health – Government of Uganda 2009:42).

4.5.3.3 Hospital mortality rates in Mawokota South health sub-district

On the basis of the monthly number of hospital deaths and the number of admissions in the hospital, the researcher estimated the monthly mortality rate as the number of deaths per 100 admissions. Information was presented by means of a line graph in figure 4.13 (below). This section analyses the mortality trends in the Mawokota South health sub-district.

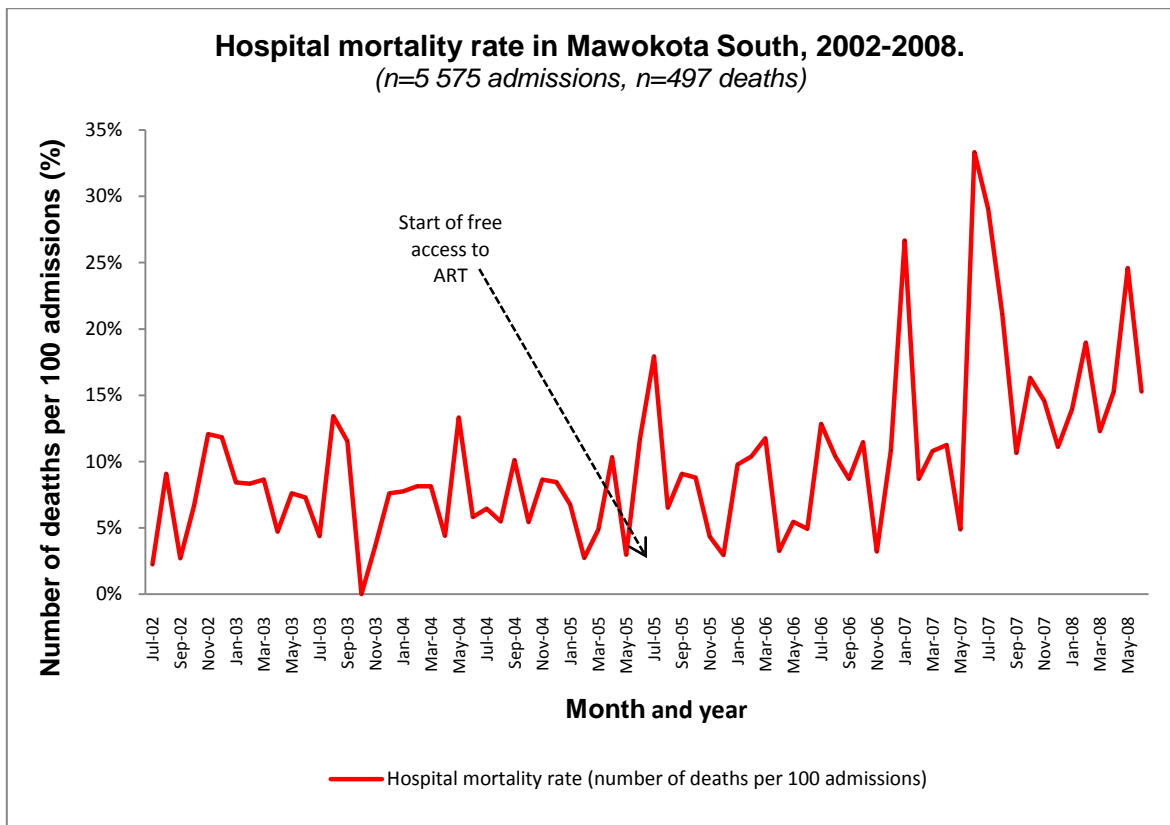


Figure 4.13: Hospital mortality rates in Mawokota South (2002-2008)

While the researcher's analysis of 497 hospital deaths showed that the mortality rate by month varied significantly from no deaths in October 2002 to 34 deaths per month in July 2007, the overall mortality rate showed a rising trend. The researcher calculated the monthly mortality rate by using the number of hospital deaths (as the numerator) and the number of hospital admissions (as the denominator).

The resultant trend showed an increase in the hospital's monthly mortality rate over the period of the study.

4.5.3.4 Hospital mortality trends and antiretroviral treatment coverage rates

The researcher estimated the number of PLWHA in need of ART in the health sub-district from the national estimates of 322 819 people who were in need of ART out of an estimated 2005 population in Uganda of 28.7 million (Ministry of Health of the government of Uganda 2009:42; United Nations Population Division 2009:[1]). This figure represented an estimated 1.1% of the total population of Uganda in need of ART, which was extrapolated retrospectively using the annual district population growth rate to determine the number of people in need of ART from June 2002 to June 2008. Using

the data on the monthly number of patients on ART accessed from ART sites in Nkozi Hospital and Buwama Health Centre, the researcher determined the monthly (total) number of patients on ART in Mawokota South health sub-district over the 72 months of the study period.

Using the total monthly number of people accessing ART per month as a numerator and the estimated monthly number of PLWHA in need of ART in Mawokota South as the denominator, the researcher determined the monthly trend of ART coverage. The key limitation of this analysis of coverage was lack of information on residents in Mawokota South accessing ART in other facilities either outside the health sub-district or from private facilities within the sub-district. Despite this limitation, the researcher was sure that more than 90% (estimated anecdotally) of the PLWHA in the sub-district were accessing ART at the public free ART sites. Therefore, the number of patients accessing free ART at the two public ART sites was representative of the number of people accessing ART in the Mawokota South sub-district.

The researcher therefore calculated the need for ART coverage among the residents of the Mawokota South health sub-district population. The ART coverage revealed a steep increase from the zero coverage of June 2005 to an estimated 60% (n=1270) coverage in June 2008.

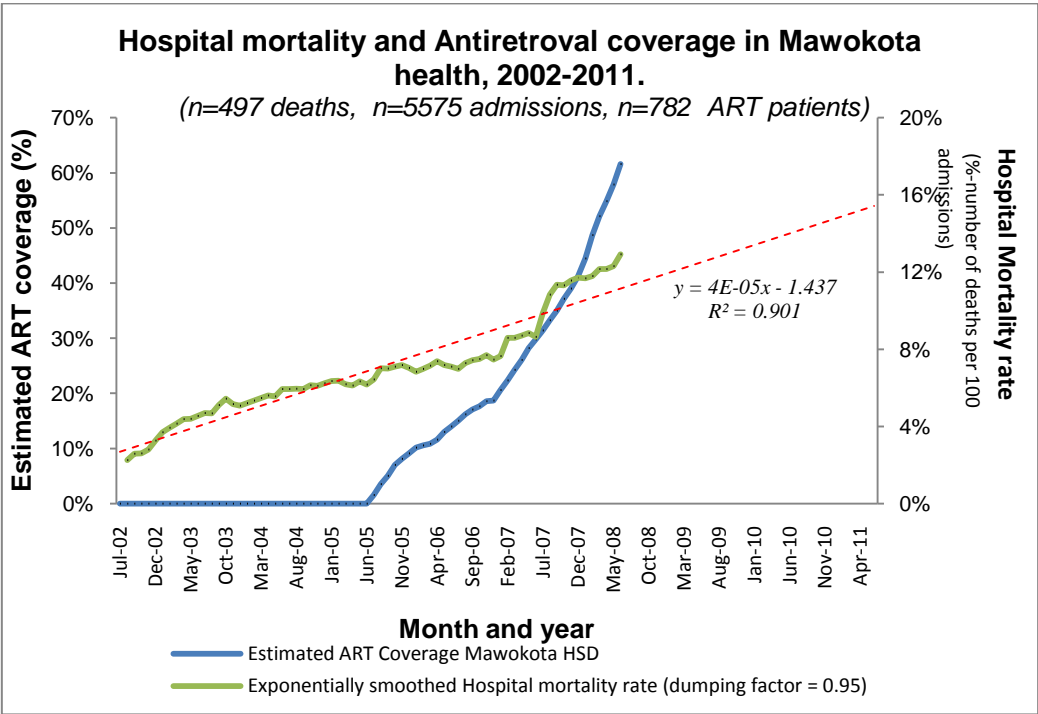


Figure 4.14: Hospital mortality and ART coverage in Mawokota South (2002-2011)

This analysis required the researcher to review the hospital records of 497 adult deaths and 5 575 adult admissions over a six-year period. The findings showed that there was a steep and rapid increase in ART coverage from 0% in June 2005 to 60% coverage in June 2008 in the Mawokota South health sub-district.

These calculations showed that the adult mortality rate increased from three (3) deaths per 100 admissions (3%) per month (in June 2002) to 11 deaths per 100 admissions (11%) in June 2008, and that the projection is that the adult will increase to 15 deaths per 100 admissions (15%) by June 2011.

Dore et al. (2002:391) reported a noteworthy reduction in mortality rates – even with a low ART coverage of 11%. In other settings, other researchers have observed that an increased access to ART in low-resource settings (with a high prevalence of HIV prevalence that is similar to the rate of prevalence that prevails in the health sub-district under study), resulted in a 10% decline in the overall mortality rate (Jahn et al. 2008:1607) and a 22% decline in the overall mortality rate in another study (that took place in South Africa) (Thaczuk & Differding 2008:[2]).

In contrast to these findings, the researcher observed that increasing levels of access to ART in Mawokota South did *not* lead to the kind of reductions in hospital mortality that were reported in a number of other studies (Carter 2005:[2]; Gomez et al 2004:[1]; Jahn et al. 2008:1607; Thaczuk & Differding 2008:[2]; United Nations 2008:28). The findings of the present study in fact demonstrated an *increasing* trend in mortality rates in the Mawokota South health sub-district.

Thus, despite the ART coverage of 60%, the hospital mortality rates revealed by this study showed an increasing trend. During the three years of free access to ART in this rural hospital setting, the researcher was unable to confirm any significant reduction in overall hospital mortality rates. Similar findings that reflected no change at all in the all-cause death rates among HIV-infected women and the number of deaths attributed to HIV/AIDS-related causes despite a significant expansion in free access to ART in the post-free ART era were reported by Smith et al. (2003:679). These findings more closely resemble the projected increase in the annual HIV/AIDS global death rate from 2.8 million (in 2002) to a pessimistic estimation of 6.5 million deaths per annum in 2030

(which represents the worst-case scenario) – even with a world-wide ART coverage of 80% by 2012 (Mathers & Loncar 2006:8).

Possible explanations for this increasing trend in mortality rates in spite of ART coverage include the late commencement of antiretroviral therapy by patients in the community who present in the terminal stages of AIDS, poor adherence to the required ART regimen on the part of PLWHA or due to facility factors. Other factors that may contribute to inadequate or no change to the trend in hospital mortality are inadequate or ineffectual targeting of HIV-infected people who urgently need ART, an inadequate awareness of the ultimate consequences of what it means to be HIV-positive, and a general ignorance among the population of how to minimize the risks of death in the community – even for people who are already infected with HIV.

The critical delays in commencing with ART could be attributed to the effects of policies and guidelines, to a shortage of the necessary medicines, a general lack of awareness in the community of the benefits of commencing ART treatment as soon as possible after infection, and a reluctance on the part of the general population to have their HIV status confirmed by means of diagnostic tests – even on the part of those who may have good reasons to believe that they are infected. A combination of all these factors lead patients to request for ART when they are really suffering from the advanced and acute symptoms that characterise the last stages of AIDS before death intervenes (Lawn et al. 2008:1905).

Because of the declining number of hospital admissions that were being recorded in the health districts in the study, and increasing mortality rates among the population at large in the post-ART era, the researcher held that there was a need for ongoing review and analysis of morbidity and mortality indicators. Although the analysis of outpatient morbidity patterns was beyond the scope of this study, it is an area that is in urgent need of further research and investigation.

In the best-case scenario, the reduction in the number of admissions in the post-free era showed that fewer and fewer adults were requiring admission to the hospital, and were able instead to be managed as out-patients. This was indicated by the fact that over time (i.e. during the six-year period and three years after that), fewer adults patients were seriously ill enough to warrant admission to the hospital. In the absence of major

policy changes in the guidelines that set out the conditions upon which an adult might be admitted to the hospital, this pattern was mainly attributed to a reduction in the severity of the various forms of morbidity that warranted admission. In high HIV-prevalence settings, the main causes of admission were malaria and HIV. Although the introduction of free access to ART and the consequent reduction in hospital admissions was thus partly attributed to an increased access to ART in the hospital, further research is needed in order to determine the actual impact of free access to ART on morbidity patterns in the district.

In the worst-case scenario, patients with mild or moderate (in terms of the severity of the disease) illnesses avoided the hospital, and they only come to the hospital as a very last resort after exhausting every other possible resource including the services of indigenous traditional healers. By the time these people present themselves at the hospital, they are nearly always critically ill and the majority of them die within 24 hours of admission or by the third day of admission.

These two scenarios, best and worst-case scenario provide possible explanations for the high and increasing hospital mortality rate amidst the declining morbidity patterns that are evident from hospital admission rates.

4.5.4 Life expectancy and the age of patients at the time of death

Although this study did not focus on life expectancy trends and HIV-specific mortality trends, one of the key findings of the study was the trend in the median age at time of patient death.

Studies have reported a five- to twenty-year reduction in life expectancy due to the effect of the HIV epidemic (Mathers, Sadana, Salomon, Murray & Lopez 2000:1687; McMichael et al. 2004:1156). In South Africa, the life expectancy of black South Africans is expected to drop by nine years by 2011 because of the effects of AIDS (Benatar et al. 2004:279). HIV/AIDS has therefore exerted a significant impact on the life expectancy of populations and has significantly reduced the life expectancy of the general population and especially the life expectancy of young adults because HIV/AIDS has significantly shifted the median age of people at the time of death and the average person's life expectancy. In high HIV-prevalence settings such as the one

reviewed on this study, HIV-related mortality has significantly contributed to premature mortality.

Changes in the median age at time of death can be caused by a variety of factors but are mainly influenced by mortality patterns in the population as a whole. Notably, the age structure of adults (who are defined in Uganda as people who are 15 years and above) in the population of Uganda and in the district and sub-districts under study, did not change significantly during the period of the study (United Nations – Population Division of the Department of Economic and Social Affairs of the United Nations 2009b:[1-2]). In essence, the major factor on life expectancy in the health sub-district is HIV/AIDS. Since the introduction of ART into settings where HIV/AIDS was among the top two main causes of death, the expectation has been that this intervention (free ART access) would exert an impact on the median age at time of death. The researcher therefore used the median age at time of death as an indicator of life expectancy patterns in the population after the introduction of free access to ART.

4.5.4.1 The median age at the time of death in Mawokota South (2002-2008)

The trend of the median age of the deceased at the time of death was a critical indicator in determining shifting mortality patterns. Analysis of these trends provides a basis for a more considered evaluation of the factors inherently associated with mortality. The researcher therefore analysed these factors, and they are presented in figure 4.15 (below).



Figure 4.15: Median age at time of death in Mawokota South (2002-2008)

In this analysis, the researcher examined trends of the age of people at time of death by making use of the median age at time of death. The median was used as a better basis for trend analysis than the mean because the median as a measure of central tendency is less sensitive to extreme values or outliers (Tustin 2005a:543). In a period of one year, the median age at time of death declined by 3.5 years (8.8%) from 40 years in 2002/2003 to 36.5 years in 2003/2004. This represented a dramatic reduction in the median age at the time of death. Thereafter, the median age at the time of death remained constant for two years at 37 years until 2004/2005. Once free access to ART had been introduced in 2005/2006, it was observed that the median age at death increased progressively by seven years over a three-year period. This represented an 18.9% increase from 37 years to 44 years by 2007/2008.

In the post-free ART era, the median age of death has increased when one compares it to the median age of death in the pre-free ART era. This means that adults died at 40 years of age and above while, in the pre-free ART era, they died at 40 years and below.

On average, patients died prematurely before the national life expectancy of 46.2 years (for adults of 15 years of age and older). These findings are similar to the findings reported by Crum et al. (2006:195), who reported that the age of patients at time of death among HIV-infected people increased from 37 to 40 years after introduction of free access to ART. Amidst minimal changes in the age structure of the population (United Nations – Population Division of the Department of Economic and Social Affairs of the United Nations 2009b:[1-2]), changes in the median age of death in the Mawokota South health sub-district were therefore largely due to changes in mortality trends which are significantly influenced by HIV/AIDS.

The determination of the median age at death therefore resulted in an indication of premature mortality trends in the health sub-district. The researcher also correlated the median age at death with the efficacy of treatment interventions, including the promptness and correctness of diagnosis and the management of illnesses (Jannerfeldt & Hörte 1988:680). An increasing median age at time of death is therefore an indirect indication of improved health and longevity of the population in the Mawokota South health sub-district – an assertion that needs to be substantiated by means of further research. Although the association between the ages of various groups of patients on ART at time of their death was beyond the scope of this study, it is a topic that will benefit from future research.

The key finding of this analysis was that free access to ART has contributed to the overall increase in median age of hospital deaths. Hospital deaths have been occurring at an older age in the post-free ART era in comparison to the ages at which they occurred in the pre-free ART era. It may therefore be asserted that the introduction of ART has contributed to people dying at an older age or as enabled them to live longer in the community that was the locus for this study.

4.5.5 Scenarios of expected mortality trends in the post-free ART era

From the possible scenarios that the researcher suggested in section 2.13, three mortality and morbidity scenarios have been selected to serve as benchmarks for assessing hospital mortality trends. The three scenarios concerned are:

1. a reduction in mortality trends
2. static or unvarying mortality trends
3. increasing mortality trends

4.5.5.1 Mortality trends based on the three scenarios of expected mortality

The introduction of ART has resulted in a profound overall decline in HIV-associated morbidity and mortality (Kessler 2003:S101). The impact of the increase in free access to ART in high HIV-prevalence settings (even when there is low coverage) was conclusively shown by the increases in the patient survival rate and reductions in the overall mortality rates. It is therefore imperative that increased access to ART in high HIV prevalence settings be directly related to a reduction in overall mortality if ART provision is to be considered a success. That was why this study focused on what the overall effect of increased access to ART might be on mortality rates in a rural setting in Uganda.

4.5.5.2 Morbidity and mortality trends in the pre-free and post-free ART eras

The findings of this study showed that this rural setting experienced a decreasing trend of adult admissions and an increasing trend in the number of hospital deaths. While the hospital experienced an increasing mortality trend, which implied that the three years of free access to ART in the Mawokota South health sub-district contributed to a reduction in morbidity patterns, free access in the area *did not significantly affect mortality trends in this rural setting*.

4.5.6 The effect of access to antiretroviral treatment on demography

Mortality as a patient outcome is influenced by a number of factors that can significantly (either positively or negatively) influence the overall trends. In this section of the report, the researcher further analysed the relationship between mortality and other factors in order to determine the level of significance among these factors in relation to mortality trends.

HIV/AIDS affects different genders and age groups differently (Ministry of Health – Government of Uganda 2009:21). In Uganda, females, for example, experience a higher prevalence of HIV in the 15-39 age group compared to males while males experience a higher prevalence of HIV compared to females in the older age brackets of 40 years old and above (Ministry of Health – Government of Uganda 2009:17, 21). It was therefore important for the researcher to analyse mortality by gender and age group in order to determine which particular gender and age group was being most affected by death and in order to investigate the PMR in the pre-free and post-free ART eras. In order to investigate the demographic trends in number of reported mortalities, the researcher compared mortality by age group and determined the association between mortality, age and gender in this rural population. According to Stanecki and Walker (2002:289), *all demographic indicators* are affected by a high HIV-prevalence rate. It has also been reported that 58% of those living with HIV/AIDS were women and that an estimated 33.3% of all PLWHA are between 15 and 24 years of age (Benatar et al. 2004:276, 283).

This analysis therefore investigated the differences in mortality in terms of different age groups and the two eras of ART access.

4.5.6.1 Hospital mortality in terms of treatment era and age at time of death

The researcher categorised the results of an analysis of 505 adult hospital deaths in terms of age groups and in terms of the relevant treatment era.

Table 4.21: Hospital mortality in terms of age group and treatment era

Age group (years)	Pre-free ART n (%)	Post-free ART n (%)	TOTAL n (%)	Variance (% change in mortality in the post-free ART era)
15-24	27(50.9) (11.8)	26(49.1) (9.4)	53 (10.5)	-2.4
25-34	69(54.3) (30.3)	58(45.7) (20.9)	127 (25.1)	-9.4
35-44	44(39.6) (19.3)	67(60.4) (24.2)	111 (22.0)	4.9
45-54	19(32.8) (8.3)	39(67.2) (14.1)	58 (11.5)	5.8
55-64	22(50.0) (9.7)	22(50.0) (7.9)	44 (8.7)	-1.8
65-74	29(51.8) (12.7)	27(48.2) (9.7)	56 (11.1)	-3.0
75-84	13(28.9) (5.7)	32(71.1) (11.6)	45 (8.9)	5.9
≥85	5(45.5) (2.2)	6(54.5) (2.2)	11 (2.2)	0.0
TOTAL	228(45.1)	277(54.9)	505	

(n=505, missing 39)

This analysis showed that, as a proportion of all deaths that occurred in the hospital, the deaths in the post-free ART era declined by 9.4% (n=127) in the 25-34 age group, by 3.0% (n=56) in the 65-74 age group, and by 2.4% (n=53) in the 15-24 age group. In contrast to this, the proportion of deaths in the post-free ART era increased by 4.9% (n=111) in the 35-44 age group, by 5.8% (n=58) in the 45-54 age group, and by 5.9% (n=45) in the 75-84 age group when one compares these figures to the mortality rates in the pre-free ART era.

Sixty-seven percent (67.2%, n=58) of the deaths in the 45-54 age group, 60.4% (n=111) in the 35-44 age group, and 71.1% (n=45) in the 75-84 age group, occurred in the post-free ART era.

The key finding that emerged from this analysis was that there was a proportional decrease in deaths in the 15-24 and 25-34 age groups, and an increase in deaths in the 35-44 and 45-54 age groups during the six-year period covered by this study. The 25-34 age group therefore experienced the highest reduction in proportional mortality while the 35-44, 45-54 and 75-84 age groups experienced a proportional increase in mortality rates.

These findings gave rise to the following question: “What was happening in these four age groups that caused such trends to emerge?” These results require an evaluation of ART access in terms of age group in order to determine the factors that have contributed to differences in mortality rates in two adjacent age groups (the 25-34 age group experienced a reduction in mortality rates while the 35-44 age group experienced an increase in mortality rates).

While an analysis of access to ART in terms of age groups is beyond the scope of this study, the data assembled above has provided an insight into the relationship between access to ART and mortality trends in terms of age groups.

4.5.6.2 *The association between mortality, age and gender*

In Uganda, life expectancy at the age of 15 and above was 46.2 years (47.6 years for females and 44.8 years for males) (Uganda Bureau of Statistics, Government of Uganda 2006c:43). In this analysis, the researcher examined mortality in terms of age and categorised all deaths into the categories of *early adult deaths* and *late adult deaths*. On the basis of an average life expectancy of 46.2 years, a death in the 15-34 age groups (which consisted of the 15-24 and the 25-34 age groups) was considered to be an early adult death, while death at the age of 35 or above was considered to be a comparatively late adult death. In order therefore to determine whether women were dying at a younger age in comparison to men, the researcher categorised the whole study population into the two categories of (1) 15-34, and (2) 35 and above. He then compared these two categories in order to determine which gender was dying at a significantly earlier adult age (all such deaths would, by any standards, be regarded as premature).

Table 4.22: The association between early adult deaths and gender

Age group (years)	Gender		Total number of deaths <i>n (%)</i>
	Female deaths <i>n (%)</i>	Male deaths <i>n (%)</i>	
15-34	82(45.8) (43.2)	97(54.2) (31.2)	179 (35.7)
35 and above	108 (33.5) (56.8)	214(66.5) (68.8)	322 (64.3)
Total	190 (37.9)	311(62.1)	501

(n=501, missing - 43)

The researcher’s analysis of 501 deaths that is set out in table 4.22 (above) showed that 43.2% (n=190) of the female deaths occurred in the 15-34 age group compared to 31.2% (n=311) of the number of male deaths that occurred in the 15-34 age group. The differences between the rate of female and male deaths in the 15-34 age group and in the 35 (and above) age groups, was found to be statistically significant ($\chi^2=6.85$, $p<0.009$). It may be concluded from these figures that when the population is categorized into the two age categories of 15-34 years and 35 years (and above), females in the 15-34 age group were at a significantly greater risk of dying more frequently in hospital when compared to males from the same age group (OR: 1.68, 95% CI[1.15-2.43]).

The researcher therefore concluded that proportionally more females were dying at a younger age compared to males in the 15-34 age group, and that females were 37% more likely to die in hospital (Risk Ratio (RR)=1.37, 95% CI[1.08-1.71]) when compared to males of the same age group.

This finding confirmed reports by the Ministry of Health of Uganda of a high HIV prevalence among females in the 15-24 age group when it reported a prevalence of 4% compared to 1% among males in the same age group (Ministry of Health – Government of Uganda 2009:21). These findings were also similar to findings in other studies that have provided evidence that HIV/AIDS affects more women at an early age than men (Benatar et al. 2004:276, 283).

4.5.6.3 HIV-related mortality in terms of gender

HIV/AIDS was responsible for between one-third and two-thirds (Lopez et al. 2006:1752) of mortality (deaths) in low-resource settings such as the one that formed the basis of this study in Uganda. This study also reviewed and compared the rates of mortality that were caused by HIV/AIDS-related causes with other causes of death in terms of gender.

Table 4.23: The association between HIV-related deaths and gender

Gender	HIV related deaths		TOTAL number of deaths n (%)
	HIV-related deaths n (%)	Non HIV-related deaths n (%)	
Female	84(43.5) (42.6)	109(56.5) (36.6)	193 (39.0)
Male	113(37.4) (57.4)	189(62.6) (63.4)	302 (61.0)
Total	197(39.8)	298(60.2)	495

(n=495, missing-49)

The researcher analyzed 495 female and male deaths and then categorised them into HIV-related and non-HIV-related deaths in table 4.23. This analysis revealed that 43.5% (n=193) and 39.8% (n=302) of female and male deaths respectively were attributable to HIV-related causes. But this difference was not statistically significant ($\chi^2=1.59$; $p=0.21$, OR=1.29 [0.89-1.86]). The results also showed that females were 16.3% less likely (CI[-44.0% - 6.6%]) to have died as a result of an HIV-related illness in comparison to males. Other studies have also reported higher HIV related deaths among men than among women (Braga 2007:326; Nicastrì, 2005:582). Studies have also reported that women exhibited better records of ART regimen adherence than men (Nachega et al. 2006:78). Women were therefore more likely to enjoy a greater degree of health and thus suffer from lower mortality rates while on an ART regimen than were men.

However, the inadequacies and deficiencies in the evaluation of all admitted patients and all mortalities of people who were at risk because of HIV/AIDS as an underlying cause of admission and death, continued to be a key limitation in the determination of the actual effect of HIV/AIDS on mortality. These limitations may have resulted in an underestimation of this effect.

Despite such limitations, the key finding of this research was that both women and men were at equal risk of dying from HIV/AIDS-related causes in this rural setting during the period under review.

4.5.7 Association between antiretroviral treatment and mortality

This section investigates the effect of ART on overall morbidity and mortality trends. Since an ARV medication stops or inhibits the replication of the HIV (WHO 2002:1), it also reduces the risk of morbidity and mortality that is associated with HIV disease. A reduction in morbidity and mortality rates is therefore the key goal of all ART programmes (Amoroso et al. 2002:323). It has been reported that, with a 39% increase in ART utilization by PLWHA, the mortality rate fell from 7.0 (in 1996) to 1.3 deaths per 100 person years (in 2004) while the incidence of AIDS-related deaths significantly declined from 3.8 (in 1996) to 0.3 deaths per 100 person years (in 2004) (Palella et al. 2006:29). This discussion therefore focussed on the effect of ART on mortality and not on the impact of ART on morbidity because the post-free ART period of three years was too short a period for any significant impact of ART to emerge and be identified.

HIV/AIDS still remains the leading cause of death in sub-Saharan Africa and continues to significantly affect morbidity and mortality trends (Lopez et al. 2006:1753). In order to compare HIV mortality in the pre-free and post-free ART eras, the researcher categorised patient deaths into HIV-related and non-HIV-related (other diagnoses) deaths and analysed the effect of ART on hospital mortality trends in the pre-free ART era in comparison to the effects in the post-free ART era in terms of gender.

This section investigates the effect of free access to ART on hospital mortality trends, and the researcher discusses the findings below.

4.5.7.1 HIV-related mortality in the pre-free and post-free ART eras

The hospital that was the locus for the study serves a rural community in Uganda where significant changes in HIV prevalence have been observed and reported. The most important factor that affects mortality trends in population catchment area of this study was a reduction in the prevalence of HIV (Ministry of Health – Government of Uganda 2009:17) and an increase in access to free ART from an estimated coverage of 0% to

60% in the three years of the post-free ART era (see figure 4.14). It is noteworthy that, even with an ART coverage rates of only 11%, a significant reduction in overall adult mortality rates have been reported (Thaczuk & Differding 2008:[2]). It is therefore apparent that even with a limited ART coverage in other settings; ART made a significant impact on mortality trends. But another study has reported a higher death rate in the early ART era in low-resource settings when this death rate is compared to that in the later ART era – a trend that demonstrated an overall decrease of 80% in a number of deaths from between 1990 and 2003 (Crum et al. 2006:195).

The present study focused on the first three years of ART access, which is considered an “early ART” access phase. This phase exhibits most of the overall effects of ART on the overall hospital mortality rate during the initial phases of free ART availability. However, in view of other factors such as the rapid increase in ART coverage and a decrease in the prevalence of HIV in rural communities in Uganda, rates of HIV-related mortality and overall mortality were expected to show a declining trend or an indication of reductions in the mortality rate (Ellman & Simms 2008:1071).

This analysis suggests even more profound indications of the possible effects of ART on mortality rates in similar settings.

Table 4.24: Association between HIV-related deaths in terms of treatment era

HIV-related death	Treatment Era		TOTAL number of deaths <i>n (%)</i>
	Post-free ART deaths <i>n (%)</i>	Pre-free ART deaths <i>n (%)</i>	
Yes	119(59.8) (41)	80(40.2) (38.3)	199 (39.9)
No (other causes of death)	171(57) (59)	129(43) (61.7)	300 (60.1)
TOTAL	290(58.1)	209(41.9)	499

(n=499, missing 45)

After the researcher had analysed 499 hospital deaths, he was able to categorise 39.9% (n=499) of the deaths as HIV/AIDS-related deaths, and therefore indicate HIV/AIDS as the leading cause of death. This finding was consistent with findings in the research of Lopez et al. (2006:1752), who provided evidence that HIV/AIDS was the cause of one-third to two-thirds of the mortality rate in sub-Saharan Africa. In this study,

the PMR of HIV-related illnesses in the post-free ART era was 41.0% (n=290) in comparison to 38.3% (n=209) in the pre-free ART era.

The difference in the prevalence of HIV as a cause of hospital death in the post-free and pre-free ART eras was not statistically significant ($\chi^2=0.39$; $p=0.53$). The possibility (risk) of an HIV/AIDS-related hospital death in the post-free ART era remained similar to the possibility (risk) of an HIV/AIDS-related death in the pre-ART era (OR=0.89, 95% CI [0.62 – 1.28]).

There was therefore no statistically significant difference in the PMR due to HIV/AIDS between the pre-free ART era and the post-free ART era.

4.5.7.2 HIV-related mortality by treatment era and gender

Significant gender differences in access to ART and in the necessity for a meticulous adherence to the ART regimen in order to obtain any benefit whatsoever, have influenced the expected rates of reduced morbidity and mortality. More females than males were accessing treatment in South African townships and 70% of the patients who were on ART were women (Boulle 2004:15). It has also been reported that women are much more likely to seek treatment than men and they therefore experience better health outcomes compared to males who live with HIV/AIDS (Wilson & Fairall 2008:489).

In another study in Ethiopia among men, the rate of AIDS deaths declined by 21.9% in comparison to a 9.3% decline experienced by women (Reniers et al. 2009:511). The researcher therefore analysed HIV-related mortality rates in this study in terms of gender in order to determine the *specific* differences in mortality rates among affected females and males.

Table 4.25: Association between female HIV-related deaths and treatment era

HIV-related deaths	Treatment Era		TOTAL number of deaths <i>n (%)</i>
	Post-free ART death <i>n (%)</i>	Pre-free ART death <i>n (%)</i>	
Yes	44(52.4) (40.7)	40(47.6) (47.1)	84 (43.5)
No (other causes of death)	64(58.7) (59.3)	45(41.3) (52.9)	109 (56.5)
TOTAL	108(56)	85(44)	193

(n=193, missing-17)

Among females, HIV as a cause of death declined by 6.4% in the post-era from 47.1% (n=85) in the pre-free ART era to 40.7% (n=108) in the post-free ART. This difference in the proportion of female deaths due to HIV-related causes in the pre-free ART and post-free ART era was, however, not statistically significant ($\chi^2=0.54$; $p=0.4$).

This analysis demonstrated that there was no significant change in the possibility of hospital HIV-related deaths for females in the post-free ART when compared to the same possibility in the pre-free ART era (OR=0.77, 95% CI [0.42-1.43]). These findings are similar to the findings in the research carried out by Smith et al. (2003:679), in which they reported that the all-cause death rates among HIV-infected women remained unchanged between the pre-ART and post-free ART eras.

In other words, free ART access in the post-free ART era did not reduce the possibility that of a female HIV-related hospital death.

Table 4.26: Association between male HIV-related deaths and treatment era

HIV-related deaths	Treatment Era		TOTAL number of deaths <i>n (%)</i>
	Post-free ART deaths <i>n (%)</i>	Pre-free ART deaths <i>n (%)</i>	
Yes	74(65.5) (41.1)	39(34.5) (32.0)	113 (37.4)
No (other causes of death)	106(56.1) (58.9)	83(43.9) (68.0)	189 (62.6)
TOTAL	180(59.6)	122(40.4)	302

(n=302, missing 27)

Table 4.26 shows that, among males in the post-free ART era, the proportional mortality that was attributable to HIV-related causes increased by 8.1% from 32% (n=122) in the pre-ART era to 41.1% in the post-free ART era (n=180). This difference was not statistically significant ($\chi^2=2.50$; $p=0.11$). The relative risk of an HIV-related death for males in the post-free ART era was 16.8% (RR=1.17, CI [0.97-1.39; OR=1.49 [95% CI [0.918-2.40]]) higher in comparison to the pre-free ART era. Males were therefore more likely to have died from an HIV-related illness in the post-free ART era compared to the possibility of this happening in the pre-free ART era. These findings indicated that a minimal or zero effect could be attributed to free ART access in relation to overall male hospital mortality trends.

Therefore, there were no statistically significant changes in HIV-related mortality for both males and females. These findings are similar to findings by Crum et al (2006:195) who reported that despite increased access to ART, the gender of patients who died in the pre and post ART eras did not substantially change among HIV-infected persons.

Despite the lack of statistically significant differences between the pre-free ART and the post-free ART era in relation to proportional mortality due to HIV for both females and males, these findings demonstrated a reduction in female mortality and an increase in male mortality. In tables 4.25 and 4.26, HIV/AIDS as a cause of death was reduced by 6.4% for females while, for males, HIV/AIDS as a cause of death, increased by a margin of 8.1%.

These findings were nevertheless important and useful for placing the understanding of the factors that are associated with female and male hospital mortality trends into a better-informed and more nuanced context of evidence-based research and speculation.

In support of the fact that HIV-related mortality rates differ in terms of gender, Sani et al. (2006:864) have reported that AIDS-related mortality among females was 43% in comparison to 37% among males. This present study also reported HIV/AIDS as the cause of death for 43.5% and 37.4% of affected females and males respectively.

In the post-free ART era, PMR due to HIV/AIDS declined among females but increased among males. These differences between proportional mortality due to HIV-related mortality in the pre-free and post-free ART access eras was not statistically significant.

4.6 CONCLUSION

This study (and this chapter in particular) investigated and discussed morbidity and mortality trends in a specific rural setting in Uganda, and identified the factors that were associated with hospital mortality. The study also provided evidence from other research and indicated where significant gaps in our overall understanding of these phenomena would benefit from more focused research so that more adequate and precise information could become available for further evidence-based decision-making.

Chapter 5 summarises the conclusions, limitations and recommendations of this study.

CHAPTER 5

Conclusions, limitations and recommendations

5.1 INTRODUCTION

Chapter 4 presented and discussed the findings of this study. This chapter focuses on the conclusions, limitations and recommendations of the study.

The researcher's purpose in conducting this study was to investigate, describe and draw conclusions about adult mortality trends since the introduction of free antiretroviral therapy in a rural hospital in Uganda. In order to achieve this objective, the researcher compiled and analysed data about adult mortality trends and the demographic characteristics of patients who had died in a rural hospital in the Mpigi district of Uganda over a period of six years (three years before and three years after the introduction of free ART). The study focused on a rural hospital in Mawokota South County, which is also referred to as Mawokota South health sub-district, and is one of the four counties of Mpigi District. The health sub-district has its headquarters in the Nkozi Hospital which provides health and medical services for a catchment population of 99 607 in the three sub-counties of Buwama, Nkozi and Kituntu (Lumala 2008:10). The researcher focused his investigative efforts on the headquarters of the health sub-district, which is a private not-for-profit hospital. This hospital (like others in Uganda) has operationalised the national health policy that was designed to provide operational responsibility and leadership for the delivery of the minimum package of health services to the catchment population (Ministry of Health – Government of Uganda 2005:20).

The researcher reviewed 544 hospital deaths that occurred in the hospital in terms of the direct and associated causes of death and any other concomitant causes that could be discerned from the hospital death records, patient files and death certificates. He then ascertained the percentages of deaths that had been caused by HIV/AIDS-related illnesses before and after free access to ART and analysed the hospital morbidity and mortality trends over the six year period and during the pre-free and post-free ART eras.

The objectives of the study were to:

1. To investigate the trends in adult hospital mortality in terms of cause in a selected rural hospital of the Mpigi district in Uganda, and also to compare the differences in adult hospital mortality trends in the same hospital in the pre-free and post-free ART eras
2. To determine the overall effect of free ART access on hospital mortality trends in a selected rural hospital of the Mpigi district in Uganda
3. To make recommendations about methods and approaches to the provision of free ARVs that would further help to reduce and minimize the prevailing high mortality rates in the hospital and in the catchment area population that is served by the hospital

This study met the objectives of the 2007/08 to 2011/12 Uganda National Strategic Plan for HIV/AIDS. The key objectives of the National Strategic plan were to mitigate the social, cultural and economic effects of HIV-infection and AIDS among individuals, households and communities, and to build effective support systems. This strategic plan highlighted the “need to generate evidence about the effectiveness, efficiency and relevance of the national HIV & AIDS response interventions so that they [could] be continuously improved” (Ministry of Health – Government of Uganda 2009:21.)

This study identified various key factors that were associated with hospital morbidity and mortality trends and the researcher made three year projections to June 2011 on the basis of the data available to him. These findings to hospital administrators and macro health care policy designers are benchmarks for calculating and evaluating future trends. An understanding of such trends and probabilities will enable those who are responsible for HIV/AIDS programmes to refine whatever elements of the current programmes need revision and adjustment, and they will also enable hospital managers to assess and review the impact that free ART is having on the mortality and morbidity trends in institutions at any given time in a future.

This chapter summarised the findings and limitations of the study, and provides recommendations for strengthening and refining the present systems that have been designed to reduce hospital mortality in low-resource rural settings. The chapter will conclude with recommendations for further research.

5.2 CONCLUSIONS OF THE STUDY

The researcher presented the conclusions in a specific order. Firstly, the researcher reviews the demographic profile of the study population. Secondly, the researcher summarises the conclusions about morbidity and mortality trends and about the factors that were associated with HIV/AIDS in the pre-free and post-free ART eras within the specific time frame delimited by this study.

The researcher based these conclusions on an analysis of findings about the number of deaths that had occurred in the rural hospital in the period between July 2002 and June 2008. He then presented the results in terms of the Uganda Government's annual financial and reporting cycle that extends from between 1 July and 30 June in each non-calendar year.

The pre-free ART years that were referred to in this analysis were those of 2002/2003, 2003/2004, 2004/2005, and the post-free ART years were those of 2005/2006, 2006/2007, 2007/2008.

5.2.1 The demographic profile of the study population

This section summarises the demographic profile of the study population in terms of age, gender, sub-county of residence, year of death and the treatment era in which the patient died.

5.2.1.1 *Age distribution of the study population*

The age distribution of the 501 deceased patients who comprised the research sample fell to the following categories: 15-24 (10.6%), 25-34 (25.1%), 35-44 (22.0%), 45-54 (11.4%), 55-64 (8.6%), 65-74 (11.2%), 75-84 (9.0%), and all those who were above 85 years at the time of their death (2.2%). Proportionally, the highest number of deaths therefore occurred in the 25-34 age group. These deaths accounted for 25.1% (n=501) of all the adult deaths that occurred in the hospital.

The age standardised Crude Death Rate (CDR) in the 15-64 age bracket, was highest in the 35-44 age group with 2.6 deaths per 1 000 population. This was the age group

that also experienced the highest HIV prevalence rate in the Ugandan population (9.2%) (Uganda AIDS Commission – Government of Uganda 2006:21). The CDR was lowest in the 15-24 age group (0.4 per 1 000 population), and highest in the 85 year age group (18.9 per 1 000 population). The researcher observed that after the age of 65 years, the hospital-based CDR doubled for every ten-year increase in the age group concerned. The overall hospital-based CDR was 9.9 per 1 000 population.

5.2.1.2 Mortality distribution in terms of age and gender

The high prevalence of HIV in the 25-39 age group was associated with a correspondingly high hospital mortality rate. While the highest number of deaths occurred among females in the 25-34 age group (30%), the highest number of male deaths occurred in the 35-44 age group (23.2%). This study revealed that 43.2% of the female deaths and 31.2% of the male deaths occurred in the first twenty years of adulthood (i.e. in the 15-34 age group). While proportionally more females died at a younger age compared to a comparable number of males in all age groups, more males than females died in the hospital itself. The least difference between the proportion of female and male mortality rates in terms of age group occurred in the 15-24 age group, where 47.2% of the deaths were those of females and 52.8% were those of males. The highest difference in the proportions of female to male mortality occurred in the 65-74 age group, in which 26.8% of the deaths were those of females while 73.2% were those of male.

5.2.2 The distribution of hospital mortality in terms of gender

With regard to the distribution of hospital mortality in terms of gender, 37.9% (n=501) and 62.1% (n=501) of the adult deaths were female and male respectively over a period of six years. More adult males therefore died in comparison to adult females – the ratio being two (1.6) male deaths for every one (1) female death.

5.2.2.1 Annual mortality trends in terms of gender

The research analysed these variations in mortality patterns in terms of gender over the six-year period of the study in order to determine any significant changes in annual mortality patterns. He therefore analysed the mortality rates in terms of year of death

and gender in order to be in a position to capture any significance in the mortality trends among adults in the hospital in terms of gender.

The annual increase in mortality rates during the two years of the pre-free ART era, revealed that while, on average, the rates of male mortality *decreased* by 3.4%, the rates of female mortality *increased* by 8.1% annually. In the post-free ART era (2005/2006 to 2007/2008), the average number of male deaths increased by 21.7% annually when compared to the average number of females deaths that increased by 4.6% annually. The researcher was therefore able to conclude that, in the post-free ART era, the number of male deaths increased by 4.7 times the number of female deaths annually during the same period. He therefore identified these figures (findings) as an issue of concern that required further investigation and analysis.

5.2.3 Distribution of deaths in terms of sub-county of residence

The hospital catchment area of three sub-counties of Nkozi, Kituntu and Buwama sub-counties in Mpigi district are bordered (in close proximity) by the sub-counties of Bulo, Butambala, Kamengo, Maddu, Kabulasoke and Lukaya sub-county in Masaka District. Because of its location and the services that it offered, the hospital was accessible to patients both within and from outside the catchment area.

5.2.3.1 Mortality in terms of sub-county of residence

The notice that the highest number of hospital deaths were of patients who had come from Nkozi (35.5%, n=510). The other hospital deaths were mainly of patients who came from Kituntu (25.1%, n=510) and Buwama (16.5%, n=510) sub-counties. The least number of deaths occurred among patients from Kabulasoke (0.8%, n=510). These findings indicated that 77.1% (n=510) of all hospital deaths during the study period were patients who resided from *within* the catchment area, while 22.9% (n=510) of the deaths had occurred among patients who were coming from *outside* the catchment area.

These statistics indicated that, in terms of access across the sub-counties, proportionally more males died in the hospital. The findings also revealed that a larger number of deaths were of people living within the Nkozi sub-county (35.5%, n=510) and

the Mawokota South county (77.1%, n=510) when one compares their figures to those of other counties.

5.2.3.2 Mortality in terms of by sub-county of residence and treatment era

The researcher also analysed differences in access to hospital services and compared these proportions to the distribution of deaths in pre-free and post-free ART eras in terms of sub-counties of residence. The findings revealed that 56.8% (n=514) of the deaths occurred in the post-free ART era in comparison to the 43.2% (n=514) that occurred in the pre-free ART era. This revealed an increase of 13.6% in the post-free ART era.

Increased access to free ART in Nkozi and Buwama sub-counties contributed to the 8.6% (n=183) and 4.2% (n=85) reduction in the mortality rate in Nkozi and Buwama sub-counties respectively. The research also noticed that mortality rates in sub-counties that did not have a designated ART site (such as Kituntu and Kamengo sub-counties) increased by 5.3% (n=129) and 2.5% (n=33) respectively in the post-free ART era.

In Mawokota South health sub-district, the major point of difference that differentiated the mortality patterns in the Nkozi and Buwama sub-counties (when compared to Kituntu sub-county) during the study period was the accessibility of free ART to patients in Nkozi and Buwama sub-counties.

The conclusion is that, in the post-free ART era, an increased access to ART in Nkozi and Buwama sub-counties contributed to the reduction in hospital deaths that was evident in these two sub-counties. Kituntu sub-county and other sub-counties which had limited access to ART, experienced a far lower reduction in mortality rates (less than 1.0% reduction) – or even an increase in the rate of the incidence of hospital deaths.

5.2.4 The association between mortality rates and patients' place of residence

Access to ART services and other general health services are influenced by a number of factors that include the distance to the health facility, the cost of transport in order to get to the health facility whenever necessary, and gender. Since the people who lived in

the hospital's catchment area were closer to the hospital itself, they were more likely to know about and, consequently, to utilize hospital services such as free access to ART.

5.2.4.1 Hospital mortality in terms of sub-county of residence and treatment era

The researcher noticed that in the post-free ART era, the factor of *residence in the catchment area* was significantly associated with a reduced likelihood that the patient would die in the hospital. In the post-free ART era, there was thus a 7.5% reduction in the number of deaths of patients from Mawokota South County – in comparison to a 7.5% increase in the number of deaths of patients whose place of residence was in sub-counties outside Mawokota South County (i.e. other sub-counties). The researcher found that the association between a patient's place of residence (their home county) and the treatment era in which they were treated (whether in the pre-free or post-free ART eras) was statistically significant ($\chi^2=4.10$; $p=0.043$). The post-free ART era was therefore associated with a reduced likelihood that a HIV-infected patient from Mawokota South County would die in the hospital. In the post-ART era, the increased access to ART in the population catchment area contributed to a 10.6% reduction in the likelihood (risk) that a patient from the hospital's immediate population catchment area would die in the hospital.

In the post-ART era, an increased access to ART in the hospital contributed to a 7.5% reduction in the rate of hospital deaths from the hospital's population catchment area, and it also reduced the likelihood (risk) by 10.6% that a patient from the hospital's population catchment area would die in the hospital.

5.2.4.2 Female and male mortality in terms of county of residence

The researcher also observed that, when one compares the pre-ART and post-ART eras, there was equal likelihood that female patients would die at the same rate as male patients in the hospital if they were resident in the Mawokota South health sub-district. But in contrast to the female patient death rate, the number of male deaths of patients from Mawokota South county declined by 11.1% in the post-free ART era. This reduction was observed to be statistically significant ($\chi^2=5.05$; $p=0.024$). Among males, in the post-free ART era, the possibility (risk) that a male patient from Mawokota South

health sub-district would die in the hospital, reduced by 14.6% (95% CI[-26.8%--2.5%]; OR=0.53, 95% CI[0.31-0.93]).

It therefore seems logical to conclude that the free access to ART in Mawokota South health sub-district was associated with an 11.1% reduction in male hospital deaths and a reduced likelihood that a male from this population catchment area would die in hospital. In contrast to this, free ART access exerted no significant effect on female hospital mortality rates in terms of the place of residence of the patient.

5.2.5 Average length of stay (ALOS) are and out-of-pocket payments

While the shortest period of hospital stay before death occurred was observed to be less than a day (24 hours), the longest period of hospital stay that was observed in this study was 67 days. High rates of mortality were in fact associated with the first day of the admission of HIV-infected patients. It is notable that 27.6% (n=490; 95% CI [23.7% - 31.8%]) of all these patient deaths occurred within in one day (24 hours) of admission while 31.6% (n=490; 27.6-36.0) of patient death occurred between two and three days of admission. Overall, 59.2% (n=490) of patients died within three days of admission, and 85.7% (n=490) of all deaths occurred within five days of admission to the hospital.

While the ALOS before death in the hospital was 4.8 days before death in the pre-free ART era, the ALOS increased to 5 days before death in the post-free ART era. Free access to ART did not therefore reduce the ALOS of patients in hospital before they died.

5.2.5.1 Observable trends in the average number of admission days before death

The researcher's analysis of average lengths of stay before death revealed that, in 2002/2003, the average number of admission days before death was six days, and that this had progressively declined to five days in 2007/2008. The researcher therefore projected that the ALOS would reach four days of admission before death by June 2011. Since the ALOS before death had revealed a decreasing trend, this may have been indicative of the increasing percentage of patients who were being admitted with critical or severe illnesses that results in their deaths in less and less days. Because of

this result and because of the risk that outlier values could influence the researcher's ALOS analysis, he preferred the median number of admission days as a measure for monitoring mortality (and therefore used it in this analysis).

5.2.5.2 *The median number of admission days before death*

When he used the median number of admissions days to determine the trend of length of hospital stay before death, the researcher observed no significant change in the median number of admission days in the three pre-free ART era when he compared them to the three years of the post-free ART access. These findings therefore indicated that an increased access to ART did not affect (i.e. either reduce or prolong) the median length of hospital stay before death occurred.

5.2.6 Out-of-pocket payments for hospital services

The out-of-pocket payment per patient death was calculated at US\$ 11.3 per death. In a population where the per capita expenditure on health is US\$ 18 and the Gross Domestic Product (GDP) in US\$ 243 (WHO 2005b:[1]), the average out-of-pocket payment of US\$ 11.3 that was required for each patient death was proportionately high. The cost of these services might therefore have functioned as a substantial obstacle that limited the willingness and ability of patients to gain timely access to health care before severe HIV-related illnesses and conditions were well established – illnesses and conditions that required emergency care and substantially increased the risk of hospital death and the cost to each patient of the necessary health care service delivery that they required.

5.2.6.1 *Average out-of-pocket payment in terms of gender and in terms of treatment era*

In the pre-free ART era, the average out-of-pocket payment that each female patient was required to make was US\$ 8.5, compared to an amount of US\$ 12.7 in the post-free ART era. For males, the average out-of-pocket payment during the pre-free ART era was US\$ 10.5, compared to the US\$ 12.7 in the post-free ART era.

The researcher detected no significant differences in the out-of-pocket payments in terms of gender in the post-free ART era, and the average out-of-pocket payment per patient death was US\$ 12.

5.2.6.2 Average out-of-pocket payments for HIV and non-HIV-related deaths

In the six year period of the study, the average out-of-pocket payment for HIV-related deaths was US\$ 11.1 in comparison to the US\$ 11.9 average payment for non-HIV-related deaths.

5.2.6.3 Average out-of-pocket payment trends (2002-2008)

Out-of-pocket payments for non-HIV-related deaths declined at an estimated US\$ 0.2 per annum ($y = -0.2x + 12.2$) from US\$ 12 per death in 2002/2003, and the researcher projected that they would further decline to US\$ 10.4 by June 2011. By contrast, out-of-pocket payments for HIV-related deaths increased at a rate of US\$ 0.2 per annum ($y = 0.2x + 9.0$) from US\$ 9.2, and the researcher projected that these would increase to US\$ 10.8 by June 2011.

These trends revealed that while HIV-related costs demonstrated an upward trend, non-HIV-related out-of-pocket payments demonstrated a declining trend during the same period.

5.2.6.4 Daily out-of-pocket payments for hospital services

The research also observed that daily out-of-pocket payments increased by 40% (from US\$ 1 to US\$ 2.5 to US\$ 3.5 over the six-year period of the study). He also projected that the daily out-of-pocket payment made by patients for each death would reach US\$ 3.7 by June 2011.

Despite free access to ART, the average amount of direct out-of-pocket payments increased by 33.3% for females from US\$ 2.4 (2002/2003) to US\$ 3.2 (2007/2008). Among males, comparable out-of-pocket payments increased by 52.0% from US\$ 2.5 (2002/2003) to US\$ 3.8 (2007/2008). From these increases in average out-of-pocket payments in a private-not-for-profit hospital, it became evident that the cost of service

delivery per mortality to the hospital and to the patients themselves was increasing and demonstrating an upward trend.

5.2.7 Associations between length of stay, out-of-pocket payments and HIV

The researcher identified a statistically significant association between length of stay (number of admission days) and out-of-pocket payments. Of the patients who had paid out-of-pocket payments, more than the average out-of-pocket payment per death of US\$ 4, were 91.3% (n=115, $\chi^2=97.2$, $p<0.0001$) of patients that died within three days of admission. Therefore, patients that died within three days of admission were more likely to have paid more than US\$ 4 as an out-of-pocket payment – compared to patients who died in any period subsequent to three days after their admission to the hospital (OR=0.06, 95% CI[0.03-0.11]).

The researcher also observed that the odds of a patient having to pay US\$ 4 or less as an out-of-pocket were similar for both HIV-related and non-HIV-related deaths. The HIV status of the patient therefore did not increase or reduce the likelihood that a patient would have to pay more or less than the average US\$ 4 out-of-pocket payment per individual mortality.

5.3 FACTORS ASSOCIATED WITH HOSPITAL MORTALITY

HIV/AIDS has exerted a significant socio-economic impact on the communities, health systems and overall development of all countries in which the prevalence of HIV infections is high. The impact of HIV on morbidity and mortality trends cannot be overemphasized.

The researcher's review of the monthly admission trends of 5 575 adult patients over a 72-month (six-year) period showed that adult admissions in the hospital decreased by 16.7% from an average of 90 admissions per month in July 2002 to 75 admissions per month in June 2008. The researcher projects that hospital admissions will drop to 65 admissions per month by June 2011. It is therefore clear that access to free ART has contributed to a 16.7% reduction in the rate of hospital admissions in a rural hospital in Mpigi District, Uganda.

5.3.1 Adult hospital mortality trends in Mawokota South

The researcher reviewed 497 deaths that had occurred over a 72 month (six-year) period for the purposes of this study. He observed that the adult death rate increased during this period by 133.3% – from an average of three deaths per month in July 2002 to an average of seven deaths per month in June 2008. He also projected that the number of deaths would increase to ten deaths per month by June 2011.

It is therefore clear that free access to ART in Mawokota South health sub-district over this three-year period did *not* reduce hospital mortality (the average number of deaths in the hospital per month).

5.3.2 The trend of deaths from Nkozi sub-county (2002-2011)

Free ART was first made accessible to patients in the hospital in the study from the beginning of June 2005. Despite the overall increase in the number of hospital deaths (from an average of three deaths per month to seven deaths per month), the average number of deaths that occurred in the hospital of residents of Nkozi sub-county showed a slow and steady decline from 2.4 deaths per month (in July 2002) to 2.2 deaths per month (in June 2008), and the researcher projects that they will decline even further to an average of 2.1 deaths per month in June 2011. This 8.7% (n=183) reduction in mortality rates in Nkozi sub-county in the post-free ART provided the researcher with an opportunity for further analysing the trends in hospital deaths in the sub-county. This reduction in the average number of hospital deaths in Nkozi sub-county indicated that an increase in access to free ART in the sub-county had at least made an initial impact on hospital mortality trends in patients from the sub-county.

5.3.2.1 Association between length of stay and HIV-related mortality

The results of the study indicated that, in the post-free ART era, 57.9% (n=266) of the patients died within three days of admission – compared to the 60.7% (n=224) who had died within three days of admission in the pre-free ART era. But this difference in mortality rates was not statistically significant (OR=0.89, 95% CI[0.62-1.28]; $\chi^2=0.3$; p=0.59). The data indicated that the risk of death within three days of admission was similar in both the pre-free and post-free ART eras.

Among females, 37.4% (n=99) of deaths that occurred within three days of admission were HIV-related deaths, compared to 49.4% (n=83) of the deaths that occurred within *more than* three days after admission. But the difference in the likelihood (risk) of HIV-related deaths for females within less than three days of admission and within more than three days after admission, was not statistically significant ($\chi^2=2.20$; $p=0.14$; OR=0.61, 95% CI[0.33-1.13]). Female HIV-related and non-HIV-related deaths were equally likely to be admitted with a variety of severe morbidities or critical illnesses that resulted in death in fewer than three days after admission.

Among males, 50% (n=100) of male HIV-related deaths occurred within three days of admission in comparison to the 65.5% (n=165) of male deaths that were attributed to non-HIV causes during the same period. This difference was statistically significant ($\chi^2=5.55$; $p=0.02$). The odds male patient who succumbed to an HIV-related death within three days after admission were 0.53 (95% CI [0.32-0.88]). HIV-related male deaths were therefore more likely to occur *within* the three days after admission than within three days or less of admission.

5.3.3 Average length of stay and out-of-pocket payments

The researcher analysed the average length of hospital stay (ALOS) and out-of-pocket payments in this study in order to determine the trends and factors that were associated with out-of-pocket payments.

5.3.3.1 Length of hospital stay in the pre-free and post-free ART eras

The average length of hospital stay was a key determinant for the cost of services to patients who were admitted and the cost for the service providers and the hospital. The objective of free access to ART is to reduce rates of morbidity and mortality. Free access to ART is also therefore expected to reduce the number of admissions and the number of hospital admission days. Such reductions in morbidity are expected to contribute to reductions in the cost of service delivery on the part of the hospital and on the part of the patients who make use of the hospital's services.

The results of the study showed that, while 27.6% (n=490; 95% CI [23.7% - 31.8%]) of the deaths occurred within 24 hours of admission, 31.6% (n=490; 27.6-36.0) occurred

within two to three days after admission. In total, therefore, 59.2% (n=490) of all patients who were admitted died within three days of admission, and 85.7% (n=490) of all these deaths occurred within five days of admission.

The high mortality rate on the first day of admission and within three days after admission is attributable to the fact that patients present with severe and critical illness and conditions on admission. It is for this reason that such a high percentage of patients die within the first day (24 hours) of admission. It is often usually the case that patients in such circumstances die even before they can be properly examined and investigated for the causes of their morbidity. This state of affairs, as has already been mentioned above, frequently resulted in the compilation of incomplete and inadequate records and death certificates because the attending physician and health care personnel had no time in which to manage the patient.

5.3.3.2 Average and median length of hospital stay

The ALOS before death was 4.9 days. The analysis of ALOS before death showed that the ALOS before death in 2002/2003 was six days, and had declined to five days in 2007/2008. The ALOS was projected by the researcher to decline even more to four days per patient before death by June 2011.

5.3.3.3 The median number of admission days

The research also evaluated the trend revealed by the median number of days of admission and used to the results of this calculation to compare trends in the pre-free and post-free ART eras. While the median number of admission days remained constant at three days of admission during the pre-free ART era, they increased to four days in 2006/2007, but declined again to three days before death (the number or level at which it stood into the pre-free ART era).

Although this analysis shows that there was no change in the number of admission days in the six-year period of the study, there was an increased variation in the number of admission days in 2007/2008. This implies that there is an increase in the number of terminal illness that warrant long admission days before death. This is a pattern that requires further research.

5.3.4 Out-of-pocket payments for hospital services

The research also calculated the average length of hospital stay in the pre-free and post-free ART eras, and used these figures to determine trends in user charges per patient before death (the so-called “out-of-pocket payments”).

5.3.4.1 Average of out-of-pocket payments per death

The researcher used out-of-pocket payments as an estimate of the direct cost of health services to patients. The average out-of-pocket payment remained almost constant for three years (from 2003/2004 to 2005/2006). In the post-free ART era, the average out-of-pocket payment per patient mortality increased steadily from US\$ 9.5 to US\$ 16.3. Therefore, while the average out-of-pocket payment in the pre-free ART era was US\$ 9.7, it rose to US\$ 12.8 per death in the post-free ART era. Out-of-pocket payments therefore increased by 61.4% from US\$ 10.1 in 2002/2003 to US\$ 16.3 per hospital death in 2007/2008.

5.3.4.2 The average out-of-pocket payment in terms of gender

In order to obtain a better understanding of the differences in out-of-pocket payments in terms of gender, the researcher carried out a separate analysis on the data relating to males and females respectively. In this analysis, the researcher compared the out-of-pocket payments made by females and males in order to determine whether there were any differences in the out-of-pocket payments made by patients in terms of gender per patient mortality. What he found out was that the average out-of-pocket payments that were being made by both males and females in the three-year, post-free ART era were in fact equal – at US\$ 12.7 per patient death event.

5.3.4.3 Average out-of-pocket payments for HIV and non-HIV-related deaths

Since HIV/AIDS was the most prevalent cause of death in the hospital, the researcher carried out a further analysis of the rates of HIV-related mortality and extent of out-of-pocket payments. What he found was that the average pre-free ART out-of-pocket payment for an HIV-related death was US\$ 11.1 compared to US\$ 11.9 for each non-HIV-related death.

5.3.4.4 Average out-of-pocket payment trends (2002-2011)

An analysis of the out-of-pocket payment trends over the six-year period of the study (2002-2008), showed that, on average, out-of-pocket payments for non-HIV-related deaths were higher than the out-of-pocket payments for HIV-related deaths. Non-HIV-related out-of-pocket payments for death declined at an estimated US\$ 0.2 per annum while out-of-pocket payments for HIV-related deaths increased at a rate of US\$ 0.2 per annum.

Out-of-pocket payments for HIV-related deaths were therefore lower than those required for the non-HIV-related deaths. HIV-related costs also increased while non-HIV-related out-of-pocket payments continued to decline.

Despite free access to ART in the hospital, the other costs of hospital care for HIV-related conditions were slowly but steadily increasing and this should be an issue of concern if the full benefits of free access to ART are to be fully understood and appreciated.

5.3.4.5 Daily out-of-pocket payments for hospital services

For females, out-of-pocket payments increased by 33.3% from US\$ 2.4 (2002/2003) to US\$ 3.2 (2007/2008). Among males, corresponding out-of-pocket payments increased by 52.0% from US\$ 2.5 (2002/2003) to US\$ 3.8 (2007/2008). The daily out-of-pocket payments for both males and females steadily increased and the increases for males were higher than increases for females. The researcher therefore projected that by June 2011, the daily out-of-pocket payments for terminally ill patients or patients with critical illness (that die in hospital) will be US\$ 3.7.

These findings reveal that the costs associated with male admissions and deaths in the hospital are significant drivers of the overall rises in the amounts that patients had to pay in out-of-pocket payments. In spite of the benefits of free access to ART, in this high-HIV-prevalence setting, the average direct out-of-pocket payment by patients for health care steadily increased by 33.3% to 52.0% over the six-year period of the study. The out-of-pocket payments per death are projected to continue increasing.

5.3.5 Association between length of stay and out-of-pocket payments

In this section, the researcher investigates the associations between length of stay and out-of-pocket payments.

5.3.5.1 Length of stay and out-of-pocket payments in the post-free ART era

The researcher identified a statistically significant association between admission days and out-of-pocket payments. Of the patients who paid an out-of-pocket payments of more than US\$ 4, 91.3% (n=115) died within three days of admission to the hospital ($\chi^2=97.2$, $p<0.0001$).

It was therefore probable that patients who died within three days of admission to the hospital are more likely to have to pay more than US\$ 4 as an out-of-pocket payment – in comparison to those patients who died in the period after three days from the time when they were admitted to the hospital (OR=0.06, 95% CI[0.03-0.11]).

5.3.5.2 Associations between HIV mortality and out-of-pocket payments

Since HIV/AIDS-related mortality was one of the top two most prevalent causes of death in the hospital, it was also a major driver of hospital care costs. The researcher therefore compared the average cost (out-of-pocket payment) of an HIV-related mortality with the average cost of anon-HIV-related mortality.

For 72.8% (n=158) of the HIV-related deaths, the out-of-pocket payments were less than US\$ 4 per hospital death – in comparison to 67.4% (n=215) for non-HIV-related deaths. The difference was not statistically significant ($\chi^2=0.99$; $p=0.32$; OR=1.29 [0.82-2.03]).

The odds therefore of having to pay US\$ 4 or less as an out-of-pocket for a hospital death (the privilege of dying in the hospital) were similar for both patients who died from HIV-related causes and those who died from non-HIV-related causes. Therefore, the HIV status of a patient did increase or reduce the probability that he or she (or the relatives) would have to pay more or less than US\$ 4 as an out-of-pocket payment to the hospital after a death occurred.

5.4 THE EFFECT OF ANTIRETROVIRAL TREATMENT ON MORTALITY

This discussion focussed on the *effect* of ART on mortality and not the *impact* of ART on mortality. This was because the post-free ART period of three years was too short a period for a significant impact of ART to be examined. The hypothesis tested in this study was; *the introduction of free antiretroviral treatment in a rural hospital lead to reduction in overall morbidity and mortality*. The overall goal of free access to ART is to reduce morbidity and mortality. The researcher therefore compiled and analysed monthly admission and mortality trends.

This study was not designed to focus on mortality trends among HIV patients or patients on ART. It was designed to identify and analyse the overall hospital adult morbidity and mortality trends in both the pre-free and post-free ART eras in terms of causes of death, number of admissions, number of deaths, and the overall hospital mortality rates.

5.4.1 Hospital morbidity and mortality trends (2002-2008) and 2011 projections

The researcher evaluated morbidity patterns in this rural setting by analysing adult admission trends. Hospital morbidity and mortality trends exert a significant impact on workload and the costs associated with service delivery in any hospital.

This section determined the effect of free access to ART on hospital morbidity and mortality trends and the findings discussed below.

5.4.1.1 Adult admission trends in Mawokota South Health sub-district

The review of monthly admission trends revealed that adult admissions in the hospital decreased by 16.7% from an average of 90 admissions per month in July 2002 to 75 admissions per month in June 2008. The researcher further projected that hospital admissions would drop to 65 admissions per month by June 2011. By June 2011, therefore, mortality trends in the hospital will have reduced by 27.8% of the 2002/2003 monthly adult admission average.

These findings indicated that free ART access contributed to the 16.7% reduction in monthly hospital adult admissions.

5.4.2 The effect of antiretroviral treatment on mortality trends

As free access to ART becomes more and more widely available, the reasons why patients seek hospitalisation and the causes from which HIV-positive patients die, have been changing and therefore need to be carefully monitored and analysed. This section summarises the causes of mortality in the pre-free ART era and compares them with the causes of mortality in the post-free ART era. The researcher also analyses and discusses the impact of ART on overall (“all cause”) mortality trends since the introduction of ARVs in this section.

5.4.2.1 The effect of antiretroviral treatment on causes of mortality

The determination of the causes of death was a key focus of this study. Over the six-year period of the study, HIV/AIDS-related illnesses were the most frequent diagnosis as a cause of death. During this period, HIV/AIDS contributed (caused) 27.1% (n=733) of all deaths in the hospital, followed by malaria with 22.6% (n=733). Respiratory tract infections (RTIs) were responsible for 10% (n=733) of the causes of death, and tuberculosis was designated as the cause of death in 9% (n=733) of all mortalities. The two conditions of HIV/AIDS and malaria were therefore reported as a direct or an associated cause of death in 49.8% (n=733) of all the hospital deaths during this period. During the same period, HIV/AIDS, malaria and RTIs were diagnosed as the most frequent cause of death in 59.7% (n=733) of all the hospital deaths.

In the post-free ART era, the frequency of HIV/AIDS as a cause of death declined by 0.7%, and tuberculosis, cardiovascular disease and meningitis declined as diagnosed causes of death reduced by 6.2%, 4% and 2.6% respectively. On the other hand, malaria as a cause of death increased by 10.1% while gastro-enteritis as a cause of death increased by 2.9%.

The slight reduction of 0.7% in the prevalence of HIV/AIDS-related illnesses as a cause of death during this period requires a more careful investigation – especially in view of the fact that, in the case 27.6% of the deaths in the hospital, the HIV status and thus the underlying component of HIV as an associated cause of death had not been evaluated or reported by laboratory diagnosis. Although this initial finding of a reduction in HIV/AIDS-related causes of death was low and was not statistically significant ($\chi^2=0.39$;

$p=0.53$), it is indicative of a trend that needs to be carefully monitored. But, as has been mentioned before, the absence of opportunities for post-mortem diagnoses of causes of death leads one to question on the accuracy of the reasons that were adduced at the time for the causes of the death of patients who died during the study period.

In addition to this, the period of three years of access to ART was too short to serve as an experimental period in which to determine the impact of ART on all of these factors. The course of the limited resources and limited diagnostic capacity available in the hospital during the study period, much of the information about causes of death might well have been inadequate and even inaccurate. It is quite possible that, in the circumstances of acute and chronic resource deprivation that prevail in the hospital, causes of death that should have been attributed to conditions such as lymphomas, malignancies and other non-HIV-related conditions were inadequately or sketchily reported.

The key findings of this analysis were an increase in malaria and gastro-enteritis as causes of death and a reduction in HIV/AIDS, tuberculosis and meningitis as causes of death in the post-free ART era when the same causes are compared to corresponding figures as causes of death in the pre-free ART era.

5.4.2.2 The effect of antiretroviral treatment on hospital mortality rates and trends

Free access to ART was first initiated in various programmes in Uganda in 2003. The extent of ART coverage in Mawokota South health sub-district (which was the locus of this study) ART coverage was estimated at 60% of the 29.3% of PLWHA.

The researcher based the hospital mortality rates on the monthly number of hospital deaths and the monthly number of admissions, and presented the resultant equation as the number of deaths per 100 admissions in any given period of the study. The researcher's analysis of 497 adult deaths and 5 575 adult admissions revealed that hospital adult mortality per month varied significantly from zero (0) deaths per month in October 2003 to the highest number, which was 34 patient deaths that occurred in the month of July 2007.

The results showed that mortality rates increased from three (3) deaths per 100 admissions (3%) per month (in June 2002) to 11 deaths per 100 admissions (11%) in June 2008. The researcher then projected that the hospital's mortality rate would increase to 15 deaths per 100 admissions (or 15%) by June 2011.

In this study, despite an ART coverage rate of 60%, the hospital mortality rates have shown a rising trend. This implies that over the three years during which patients have had free access to ART in this rural hospital setting, no notable changes in the overall hospital mortality rates have yet been observed. The researcher therefore concluded that free access to ART in Mawokota South health sub-district during this period had not significantly affected hospital mortality trends.

This study has, in fact, demonstrated that this hospital has experienced both a declining trend in adult admissions and an increasing trend in the number of hospital deaths.

5.4.3 The age at time of death

Although this study was not designed to focus on life-expectancy rates and HIV-specific mortality trends, one of the key findings of the study was the trend in median age at time of death. The trend of age at the time of patient death is a critical indicator of shifts in mortality trends, and provides a basis for deeper evaluations of the inherent factors that are associated with mortality trends. The researcher therefore analysed the trend of age at time of patient death by using the median age of the patients at the time of their deaths.

In a period of one year, the median age at time of death declined by 3.5 years (8.8%, n=40 years) to 36.5 years (2003/2004), and remained steady at 37 years in 2004/2005. With the introduction of free access to ART, deaths were occurring later (at an older age) every year. The median age at death increased by 7 years (18.9% increase) in a three year period from 37 years (2004/2005) to 44 years (2007/2008). On average, therefore, patients died prematurely before the national life expectancy age of 46.2 years for all Ugandan adults (i.e. for everyone who was 15 years and older).

The key finding of this analysis was that free access to ART contributed to an overall increase in life expectancy analysed by use of the median age at time of death in the hospital.

5.4.4 Demographic effects of antiretroviral treatment

The researcher also analysed mortality in terms of gender and age group in order to determine the particular gender and age groups that were dying in hospital and the change in the PMR in the pre-free and post-free ART eras.

5.4.4.1 Hospital mortality in terms of treatment era and age

When the researcher categorised adult hospital deaths in terms of the age groups of the patients concerned and in terms of the treatment era, he found that, in the post-free ART era, hospital deaths declined by 9.3% (n=127), 3.0% (n=56) and 2.5% (n=53) in the 25-34, 65-74 and in the 15-24 age groups respectively.

By contrast, the number of deaths increased by 4.9% (n=111), 5.8% (n=58) and 5.9% (n=45) in the 35-44, 45-54 and the 75-84 year age groups respectively in the post-free ART era, when one compares these figures to the corresponding figures for the pre-free ART era.

The key finding of this analysis was a proportional decrease in the number of deaths in the 15-24 and 25-34 age groups, and a proportional increase in the 35-44 and 45-54 age groups in the post-free ART era, when one compares these figures to the corresponding figures in the pre-free ART era. This is an indication that hospital death are reducing in the younger adults (15-34) and increasing in the middle age adults (35-54). These trends also need careful monitoring to determine the factors associated with these patterns.

5.4.4.2 The associations of between mortality, age and gender

The researcher observed that 43.2% (n=190) of female deaths occurred in the 15-34 years old age group as opposed to 31.2% (n=311) of males deaths that occurred in the same age group. The difference between female and male deaths in the 15-34 age

group, and in the 35 year old and above age group, was statistically significant ($\chi^2=6.85$, $p<0.009$). It was more probable or likely that females in the 15-34 age group would die in the hospital compared to males in the same age group (OR: 1.68, 95% CI[1.15-2.43]). What the researcher found was that proportionally more females were dying at a younger age in comparison to males, and that they had a 37% (Risk Ratio (RR)=1.37, 95% CI[1.08-1.71]) higher chance of dying if they were in the 15-34 age group compared to their male counterparts. The researcher therefore concluded that more females in Mawokota South health sub-district were dying at an early adult age in the 15-34 age group than males in the same age group.

5.4.4.3 HIV-related mortality in terms of gender

When the researcher categorised all deaths into HIV-related and non-HIV-related deaths, he noticed that 43.5% (n=193) and 39.8% (n=302) of female and male deaths respectively were HIV-related. This difference was not statistically significant ($\chi^2=1.59$; $p=0.21$, OR=1.29 [0.89-1.86]). The results however indicated that females were 16.3% (CI [-44.0% - 6.6%]) less likely (lower risk) to die of an HIV-related illness than males in the same age group.

In spite of these indications, it should always be borne in mind that the inadequate evaluation of the involvement of all the HIV-related factors in the admission of patients to hospital and all subsequent mortalities, remains a key limitation of this study as one attempts to determine the actual effect of HIV/AIDS on mortality rates. Because of the acute lack of resources in the hospital that was used for the study and the enormous number of critically ill patients who were being admitted at the time, they may well have been an underestimation of HIV-related factors as physicians and health care personnel attempted to determine the precise causes of death among so many fatalities. It is reasonable to admit that, at the time of death, the HIV status of at least 27.6% (n=544) patients was either undiagnosed/(undetermined) or not recorded in hospital records.

Despite these limitations, the key finding from this analysis was that women and men had an equal chance of dying from an HIV/AIDS-related condition or illness in this rural setting during the period under review.

5.4.5 Antiretroviral treatment coverage and mortality trends (2002-2008)

HIV/AIDS is the leading cause of death in sub-Saharan Africa and continues overwhelmingly to affect morbidity and mortality trends in this region of the world (Lopez et al. 2006:1753). In order to compare trends in HIV mortality in the pre-free and post-free ART eras, the researcher categorised all deaths in the sample into those caused by HIV-related conditions and those caused by non-HIV-related conditions. He then analysed the effects of ART on hospital mortality trends in the pre-free ART era and compared them to the hospital mortality trends in the post-free ART era in terms of the gender of the deceased patients.

5.4.5.1 HIV-related mortality in the pre-free and post-free ART eras

In this study, the researcher focused on the first three years during which access to free ART in Uganda was made available to all patients who asked for it. This period is considered to be the "early" ART access phase because most of the effects that the free availability of ART would later exert on overall hospital mortality trends were still in their incipient initial phases. In other words, how the free availability of ART would later affect morbidity and mortality trends among affected and new patients, had not yet had sufficient time in which to manifest themselves to the extent that they would later in the implementation of free access to ART.

In the six-year study period, the PMR caused by HIV/AIDS was 39.9% (n=499). This made HIV/AIDS the most prominent direct and associated cause of death among patients who were dying. But in the post-free ART era, the PMR caused by HIV-related illness was 41.0% (n=290) in comparison to the 38.3% (n=209) in the pre-free ART era.

In the post-free ART era, the PMR caused by HIV/AIDS related illness compared to non-HIV-related illnesses increased by 2.7%. The differences in HIV-related conditions as a cause of hospital death in the post-free and pre-free ART eras, was not statistically significant ($\chi^2=0.39$; $p=0.53$).

If one therefore compares the pre-free and post-free ART eras, there was no observable difference in the PMR caused by HIV/AIDS. The possibility (risk) of an HIV/AIDS-related hospital death in the post-free ART era was therefore similar to the

degree of risk that patients had of dying from an HIV/AIDS-related cause in the pre-ART era (OR=0.89, 95% CI[0.62 – 1.28]).

One therefore has to conclude that free access to ART did not reduce the probability that an HIV-infected patient would die from a HIV/AIDS-related cause in the post-free ART era.

5.4.5.2 HIV-related mortality in the pre-free and post-free ART eras in terms of gender

Among females, HIV as a cause of death declined by 6.4% in the post-free ART era from 47.1% (n=85) in the pre-free ART era to 40.7% (n=108) in post-free ART era. But this difference was not statistically significant ($\chi^2=0.54$; $p=0.4$). This analysis shows that, if one compares the post-free ART era with the pre-free ART era, there was no significant change in the probability that an HIV-infected female would die in hospital from a HIV-related cause (OR=0.77, 95% CI [0.42-1.43]). In other words, ART access in the post-free ART access era did not reduce the probability that a female would die of an HIV-related cause.

Among males, however, in the post-free ART era, the proportional mortality due to HIV-related illnesses increased by 8.1% from 32% (n=122) in the pre-ART era to 41.1% (n=180). Although this difference was also not statistically significant ($\chi^2=2.50$; $p=0.11$), the relative risk that males would die from an HIV-related cause in the post-free ART era increased by 16.8% (RR=1.17, CI [0.97-1.39; OR=1.49 [95% CI [0.918-2.40]) in comparison to the probability that they would die from the same causes in the pre-free ART era. Males were nevertheless more likely to have died from an HIV-related illness or condition in the post-free ART era than in the pre-free ART era.

These findings show that the PMR caused by HIV-related conditions and illnesses in the post-free ART era was not significantly different from the PMR in the pre-free ART era. Despite this lack of a statistically significant differences in the mortality rates attributable to HIV/AIDS-related causes for both females and males in both the pre-free ART era and post-free ART eras, these findings nevertheless indicate that there was a reduction in the female mortality rate and an increase in the male mortality due to HIV-related

conditions in the post-free ART era. While HIV/AIDS as a cause of death declined by 6.4% for females, it increased as a cause of death for males by 8.1%.

While the advent of free ART access did not therefore reduce the proportion of mortality rates among males and females because of HIV-related illnesses and conditions, there was some indication in the data that males stood a higher chance of dying from HIV-related causes in the post-free ART era in the sample that was analysed by the researcher.

5.4.6 Scenarios for expected mortality trends in the post-free ART era

The researcher defined three mortality and morbidity scenarios as benchmarks for the assessment of future hospital mortality trends. These three scenarios are:

- a reduction or decline in mortality trends
- stagnant or static mortality trends
- increasing mortality trends

5.4.6.1 Morbidity and mortality trends in the pre-free and post-free ART eras

The findings of this study revealed that this particular rural setting experienced a declining trend in adult admissions and an increasing trend in the number of hospital deaths during the years covered by this study. Therefore, on the overall, the hospital experienced an increasing mortality rate trend. This implied that while the three years of free access to ART in Mawokota South health sub-district contributed to a reduction in morbidity rates, it did not significantly affect mortality trends.

5.5 SUMMARY OF FINDINGS

- The age distribution of 501 deaths was 15-24(10.6%), 25-34(25.1%), 35-44(22.0%), 45-54(11.4%), 55-64(8.6%), 65-74(11.2%), 75-84(9.0%), and the group of those above 85 years old (2.2%).
- The research sample from a hospital mortality records was divided in the following way in terms of gender: 37.9% (n=501) of the deceased adults were female and 62.1% (n=501) of the deceased adults were male (an adult in

Uganda is defined as someone of 15 years or older). More adult males than females died. The ratio of deaths in the study sample was two (1.6) male deaths to one (1) female death.

- The age-standardised Crude Death Rate (CDR) in the 15-64 age bracket was highest in the 35-44 age group at 2.6 deaths per 1 000 of the population. Proportionally, the highest number of deaths occurred in the 25-34 age group, and the deaths in this age group accounted for 25.1% (n=501) of all the adult deaths in the hospital.
- The findings from the study revealed that the 77.1% (n=510) of all the hospital deaths were of patients who resided in the hospital's population catchment area while 22.9% (n=510) of the patients who had died in hospital had come from outside the hospital's population catchment area.
- The findings revealed that 56.8% (n=514) of all the deaths in the sample occurred in the post-free ART era in comparison to 43.2% (n=514) of the deaths that had occurred in the pre-free ART era. This revealed an increase of 13.6% in the mortality rate in the post-free ART era.
- The highest number of deaths among females occurred in the 25-34 age group (30%), while the highest number of deaths among males occurred in the 35-44 age group (23.2%). This study showed that 43.2% of the female deaths and 31.2% of the male deaths occurred in the first twenty years of what can be defined in Uganda as 'early' adulthood (i.e. in the 15-34 age group). Proportionally, therefore, a larger number of females died at a younger age in comparison to males.

5.5.1 Summary of findings in terms of the objectives of the study

In this study, the provision of free ART coverage increased from zero (0) until an estimated 60% of 29.3% of PLWHA in the hospital's catchment area in which free ART was available to the population. This study therefore took place against a background of a rapid increase in ART coverage in this particular rural setting, and the researcher analysed as thoroughly as possible the morbidity and mortality trends that he observed from the data that was collected.

5.5.5.1 Objective 1

To investigate the trend of adult hospital mortality in terms of cause and to compare these causes and trends in the pre-free ART to causes and trends in the post-free ART/HAART era in a selected rural hospital of the Mpigi district in Uganda.

- In the post-free ART era, the frequency of HIV/AIDS as a cause of death declined by 0.7%, and tuberculosis, cardiovascular disease and meningitis also declined as a cause of death by 6.2%, 4% and 2.6% respectively. On the other hand, malaria increased as a cause of death by 10.1% and gastro-enteritis increased as a cause of death by 2.9%.
- When the researcher compared the pre-free and post-free ART eras, he observed no significant difference in the proportional rates of mortality due to HIV/AIDS. He calculated that the probability (risk) of dying from an HIV/AIDS-related cause in hospital in the post-free ART era was similar to the probability (risk) that the patient would die from an HIV/AIDS-related cause in the pre-free ART era (OR=0.89, 95% CI[0.62 – 1.28]). He therefore concluded that free access to ART in the circumstances that prevailed in the study had **not** reduced the probability that a patient would die from a HIV/AIDS-related cause in the hospital.
- HIV as a cause of death among females declined by 6.4% in the post-ART era from 47.1% (n=85) in the pre-free ART era to 40.7% (n=108) in post-free ART era. This difference was, however, not statistically significant ($\chi^2=0.54$; $p=0.4$). In other words, access to free ART did not reduce the probability that a female would die from an HIV-related cause in the hospital in the post-free ART access.
- In the post-free ART era, among males, the proportional mortality attributable to HIV-related illnesses and conditions increased by 8.1% from 32% (n=122) in the pre-free ART era to 41.1% in the post-free ART era (n=180). Although this difference was not statistically significant ($\chi^2=2.50$; $p=0.11$), the relative risk of an HIV-related death in the post-free ART era for males increased by 16.8% (RR=1.17, CI [0.97-1.39; OR=1.49 [95% CI [0.918-2.40]]) in comparison to the rate that prevailed in the the pre-free ART era. Males were therefore more likely to have died of an HIV-related illness in the post-free ART era than in the pre-free ART era.

5.5.5.2 Objective 2

To determine the overall effect of free ART access on hospital mortality in a selected rural hospital of the Mpigi district in Uganda.

- The researcher's analysis of the two years of the pre-free ART period revealed that, on average, the male mortality decreased by 3.4% while the female mortality increased by 8.1% annually during the period of the study. In the post-free ART era (2005/2006 to 2007/2008), the number of male deaths increased by 21.7% annually in comparison to the number of females deaths which increased by 4.6% per annum. In the post-free ART era, the annual increase in number of male deaths was 4.7 times greater than the number of comparable female deaths. This high incidence of male mortality was therefore identified by the researcher as an issue of concern.
- An increased access to free ART in Nkozi and Buwama sub-counties contributed to a 8.6% (n=183) and 4.2% (n=85) reduction in mortality in Nkozi and Buwama sub-counties respectively. Mortality in sub-counties that did not have a designated ART site (counties such as like Kituntu and Kamengo) experienced a 5.3% (n=129) and 2.5% (n=33) respective increase in their mortality rates.
- In the post-ART era, the increased access to ART in the hospital contributed to a 7.5% reduction in the overall number of hospital deaths from the hospital's population catchment area. Free ART access also contributed to the reduction in the likelihood (risk) of a hospital death for patients from the hospital's population catchment area by 10.6%.
- The researcher's review of monthly admission trends revealed that the adult admission rate decreased by 16.7% from an average of 90 admissions per month in July 2002 to 75 admissions per month in June 2008. The researcher projected that hospital admissions would drop to 65 admissions per month by June 2011. Free ART access therefore contributed to a 16.7% reduction in hospital admissions in a rural hospital in Mpigi District, Uganda, during the period of study.
- During a period of one year in the pre-free Art era, the median age at time of death declined by 3.5 years (8.8%, n=40 years) to 36.5 years (2003/2004), and remained at 37 years in 2004/2005. But after free access to ART had been

introduced over a three-year period, the median age at death increased by 7 years (18.9%) from 37 years to 44 years (2007/2008).

- Adult deaths increased by 133.3% from an average of three deaths per month in July 2002 to seven deaths per month in June 2008. The researcher projected that the number of deaths per month would increase to ten deaths per month by June 2011. Free access to ART in Mawokota South health sub-district over a three-year period therefore did not reduce the hospital mortality rate (i.e. the number of deaths in the hospital per month).
- The results of the study showed that mortality rates increased from three (3) deaths per 100 admissions (3%) per month (in June 2002) to 11 deaths per 100 admissions (11%) in June 2008. The researcher projected that the hospital mortality rate would increase to 15 deaths per 100 admissions (15%) by June 2011.
- In the post-free ART era, hospital deaths declined by 9.3% (n=127), 3.0% (n=56) and 2.5% (n=53) in the 25-34, 65-74 and the 15-24 age groups respectively. By contrast, proportionally, the number of deaths increased by 4.9% (n=111), 5.8% (n=58) and 5.9% (n=45) in the 35-44, 45-54 and 75-84 year age groups respectively in the post-free ART era compared to the number of deaths that occurred in the pre-free ART era.
- Although the number of admission days spent in the hospital before death remained constant at three days of admission during the pre-free ART, they increased to four days in 2006/2007 and fell back again to the pre-free ART era rate of three days in 2007/2008. The trend in the number of admission days before death showed no significant change in the number of admission days in pre-free ART era in comparison the number of admission days in the post-free ART access. One may therefore conclude that an increased access to ART did not affect (reduce or prolong) the length of hospital stays on the part of patients before death intervened.

These findings indicate that over the three years during which patients had free access to ART in this rural hospital setting, the researcher was able to observe noteworthy changes in morbidity and mortality rates –in spite of the fact that the overall hospital mortality rates did not decline or show any downward trend. One may therefore conclude that free access to ART in Mawokota South health sub-district in the context of this research did not significantly decrease overall hospital mortality trends.

5.5.5.3 Summary of factors associated with hospital mortality

- While the shortest period of hospital stay before death was less than a day, the longest period of hospital stay observed in this study was 67 days.
- The highest mortality rates occurred during the first day (24 hours) after admission, with 27.6% (n=490; 95% CI [23.7% - 31.8%]) of deaths occurring within in one day (24 hours) of admission while 31.6% (n=490; 27.6-36.0) occurred between two to three days after the patient had been admitted. What the researcher observed was therefore that 59.2% (n=490) of all patients died within three days after admission and 85.7% (n=490) of all deaths occurred within five days of admission.
- In the post-free ART era, 57.9% (n=266) of patients died within three days after admission compared to 60.7% (n=224) of patients who died in the same period in the pre-free ART era. Since this difference was not statistically significant (OR=0.89, 95% CI[0.62-1.28]; $\chi^2=0.3$; p=0.59), the risk of death within three days of admission was similar during the pre-free and the post free ART eras.
- Female HIV-related and non-HIV-related patients were equally likely to be admitted with severe or critical illnesses and conditions that resulted in their death within less than three days of admission to the hospital.
- Among males, 50% (n=100) of HIV-related deaths occurred within three days of admission to the hospital – compared with 65.5% (n=165) of patients who died from non-HIV-related causes. This difference was statistically significant ($\chi^2=5.55$; p=0.02). The odds that a male would die from an HIV-related cause within three days of being admitted to hospital were therefore 0.53 (95% CI [0.32-0.88]). Males were also more likely to die from HIV-related causes than females within more than three days after they had been admitted to hospital.
- The ALOS before death in the hospital was 4.8 days before death in the pre-free ART era and 5 days before death in the post-free ART era. Free access to ART therefore contributed to no reduction in the ALOS in hospital before death.
- The average out-of-pocket payment that each patient was required to pay was US\$ 11.3 per patient death.
- In the post-free ART era, the researcher could detect no differences in out-of-pocket payments in terms of gender, and the average out-of-pocket payment for each patient death was US\$ 12.

- In the six-year period of the study, the average out-of-pocket payment for HIV-related deaths was US\$ 11.1 in comparison to the US\$ 11.9 that patients who died from non-HIV-related causes were required to pay.
- Out-of-pocket payments for non-HIV-related deaths declined from US\$ 12 per patient death in 2002/2003, and the researcher projected that they would further decline to US\$ 10.4 by June 2011. By contrast, out-of-pocket payments for HIV-related deaths increased from US\$ 9.2 per patient, and the researcher projected that these payments would increase to US\$ 10.8 by June 2011. The trends revealed that HIV-related costs demonstrated an increasing trend while non-HIV-related out-of-pocket payments demonstrated a reducing trend.
- Out-of-pocket payments increased by 61.4% from US\$ 10.1 in 2002/2003 to US\$ 16.3 per patient death. The average out-of-pocket payments that males and females had to pay in the three-year, post-free ART era were equal at US\$ 12.7 per patient death event. Despite free access to ART, the other costs involved in the care of HIV-related conditions increased, the researcher identified this as an issue of concern if the successful outcomes of free access to ART were to be fully realised in the context of the community and the country as a whole.
- The odds of having to pay US\$ 4 or less (US\$ 4 was the average out-of-pocket payment per death) as an out-of-pocket were similar for both HIV-related and non-HIV-related deaths. The HIV status of the patient did increase or reduce the risk of the patient having to pay more or less than US\$ 4 as an out-of-pocket payment prior to death.
- When the researcher categorised the deaths in terms of HIV-related and non-HIV-related causes, he found that 43.5% (n=193) and 39.8% (n=302) of female and male deaths respectively were HIV-related. This difference was not statistically significant ($\chi^2=1.59$; $p=0.21$, OR=1.29 [0.89-1.86]). The results, however, showed that females were 16.3% less likely than males (CI [-44.0% - 6.6%]) to have died from an HIV-related illness.

The analysis of the data in this study revealed the following findings:

- Hospital admissions were declining and continuing to decline.
- Hospital mortality rates were increasing and continuing to increase.
- The number of deaths in the two sub-counties that had been designated as ART sites were reduced and each revealed a downward trend.

- The more free access to ART is made available at the sub-county level, the more it will contribute to a reduction in overall mortality rates.

The hypothesis that the researcher tested in this study was formulated as follows: *The introduction of free antiretroviral treatments in a rural hospital lead to a reduction in the overall morbidity and mortality (in the hospital).*

The results revealed that the mortality rates increased from three (3) deaths per 100 admissions (3%) per month (in June 2002) to 11 deaths per 100 admissions (11%) in June 2008. The researcher projected that hospital mortality rates would increase to 15 deaths per 100 admissions (15%) by June 2011.

In this study, despite the ART coverage of 60%, hospital mortality rates showed a rising trend. This therefore implies that the provision of free access to ART in this rural hospital setting over a period of three years made no observable changes to the overall hospital mortality rates that prevailed in the hospital at the beginning of this study. Free access to ART in Mawokota South health sub-district therefore exerted no significant effect on mortality trends in the hospital during the period of this study.

5.5.5.4 Objective 3

To make recommendations that would enhance the provision of free ARVs so that the current high mortality rates (see section 5.7) could be reduced and minimised.

5.6 LIMITATIONS

The fact that the review of the effects of ART on hospital mortality trends was not able to be extended beyond the three-year period of the study, was one of the key limitations of the study. After a period of only three years of free access to ART, the possibility of observing a definite effect on the mortality rate in a particular hospital is fairly low. It was necessary, however, and important to undertake this analysis at this particular juncture in the implementation process so that hospital managers and ART programme administrators are enabled to review the effects of free access to ART on their patients on the basis of the data presented in this study and thus to develop targeted interventions that will minimise rates of morbidity and mortality.

A determination of the degree of efficiency with which free ART services to inpatients are managed by hospital administrators and other health care workers is also a key determinant of mortality trends. Although this factor was beyond the scope of this study, it is an area that urgently requires further research.

The inadequate and incomplete mortality records in the hospital's archives also constituted a major limitation on the degree to which these findings could be asserted with a high degree of confidence. Eight percent (8.3%, n=544) of the deaths were unaccompanied by any record of a direct or an associated cause of death while 27.6% of the deaths that have occurred in the hospital had not been assessed or described in terms of the possibility of HIV involvement. This indicated that the health system was losing immensely valuable opportunities for screening patients for HIV. All patients admitted to hospital need to be screened for HIV infections so that targeted interventions can be designed to reduce the extremely high rates of mortality in this era of free access to ART.

The diagnoses that physicians and other health care workers used to reach their conclusions were based on clinical symptoms and signs and on whatever laboratory tests were available in the hospital at the time. The invariable absence of post mortem diagnoses limited the accuracy of the description of the recorded causes of patient deaths, and this was a key limitation that hampered the degree of accuracy with which the researcher could present his conclusions on the basis of these results.

Whatever hospital-based mortality records were available to the researcher constituted the only documentary evidence that describe the causes of patient deaths throughout the six-year period of the study. It was these records that provided the data that enabled this analysis, and, in spite of all limitations, they will provide important evidence for informing whatever future interventions will be designed to reduce the high rate of adult mortality in rural health facilities.

5.7 RECOMMENDATIONS

The evidence that the HIV/AIDS male mortality rates were disastrously high and that they were increasing at an alarming rate in Uganda and throughout all of sub-Saharan Africa motivated the researcher to undertake this research. The researcher focussed on the factors that were contributing to the high rate of hospital deaths throughout the region by gender and more specifically among males. It was therefore the researcher's purpose to investigate and design specifically targeted interventions to develop and facilitate increased access to health services that will ensure that freely available ART minimises the catastrophic rate of mortality throughout the region.

It was also one of the aims of the researcher that the findings from this study would provide benchmarks for HIV programme managers and hospital managers so that they would be able to monitor the impact of the effect of free ART on hospital and community mortality trends from the basis of solid research. The parameters on which the researcher focused included ALOS in hospital, the attributed causes of death, the a median age at death and the amount of out-of-pocket payments that patients while accessing hospital services in Uganda. Other parameters studied included the age and gender distributions of hospital deaths, the rates of ART coverage in proportion to the number of people in the community, and the specific HIV/AIDS mortality rates in the context of the overall hospital mortality rates. It is vitally important for health care managers and administrators to be constantly aware of past, future and projected mortality rates and to compare the mortality rates in their own institutions with these benchmarks. The researcher therefore recommends that all health care and hospital administrators and physicians monitor the impact of ART on mortality trends in the various categories that he has examined throughout the course of this study.

The alarmingly high and increasingly unacceptable hospital mortality rates indicate the urgent need for extensive reviews of the capacity of hospitals to manage medical emergencies and the capacity and efficiency of the management of referral systems. The findings adduced in the study also indicate that there is an urgent need for extensive reviews of the guidelines, policies and community mobilization strategies that are currently in place in sub-Saharan Africa, for early diagnosis and treatment of people who are infected with HIV is the most important single factor in the long-term management of this lethal virus. Although what the average person in Uganda knows

and understands about HIV and its possible consequences for human health and survival are much better than in many other places in Africa, it is nevertheless important to determine just how well the public understands the benefits of ART so that they can be motivated to access treatment as early as possible. The patient's understanding of ART benefits is a motivation to adhere strictly to ART treatment requirements and comply meticulously with the ART dosage regimen so that they are able to maintain a desirable standard of life and health.

The extremely high mortality of patients who die within their first day (24 hours) of admission to hospital also needs to be urgently investigated. Other factors that require urgent investigation, review and monitoring are the following: the capacity of the hospital to manage severe and/or critical illnesses and conditions; the investigative capacity of individual hospitals and health care centres and clinics; the capacity of emergency support services to respond efficiently in critical situations; continuity in the supply and quality of medicines and other necessary hospital equipment; the ability of hospitals to maintain and service all their equipment and other facilities in such a state of readiness that the lives of patients will not be endangered by malfunctioning or dysfunctional equipment; the ongoing training and education of existing nursing and medical personnel in the latest techniques of HIV/AIDS and other kinds of patient care so that both they and their patients will be able to benefit from the latest evidence-based findings from research conducted throughout the world; the establishment of health promotion activities that will encourage patients to seek medical attention before the most severe complications of HIV/AIDS illness have reduced their health status to an unmanageable degree; the targeting of ART access to that sector of the population that is most in need of ART (such people would include, for example, patients who are presenting with stage four HIV disease), and assisting such patients to participate in HAART and other forms of necessary treatment before their immunity becomes too severely compromised.

Possible explanations for the increasing mortality rates that afflict sub-Saharan Africa more than any other region in the world include late access to health services and the arrival of patients who present with such severe forms of critical illness that they die soon after being admitted to hospital. There is an enormous need in the community and in all out-patients departments to test people for their HIV status and the screening of all adults will go a long way in ensuring that people at the highest risk of HIV related

mortality are identified and managed. In settings where HIV infection is widely prevalent, a significant proportion of the patients who are already receiving treatment in a hospital are already highly likely to be HIV-positive. If, in such instances, they are treated in a hospital without being screened for HIV, they will miss the vitally important opportunity to access the treatment that they need and will give them an opportunity to receive free ARV and enjoy a reasonable standard of life and health in the future. When health care providers miss the opportunity of the early identification of HIV-positive patients, they increase the probability that such patients will eventually only access ART so late that they will probably die within days or hours of being admitted to hospital.

The researcher came to the conclusion that the mortality rate was highest in the 24-44 age group and among males. If health care administrators wish significantly to minimise mortality trends, they need specifically to focus (without forgetting all of the patients who are at risk of death because of HIV/AIDS-related illnesses) on efforts to reach high-risk males and could target the 24-44 age group in both genders. As a result of the findings in this study, the evaluation of ART access in terms of age groups so that researchers will be able to determine the factors that contribute to reducing or increasing mortality with reference to gender and age group are identified.

In order to deliver a successful ART programme to those who need it, the costs involved in health services will be a critical factor that needs to be considered. Because of the poverty and financial constraints with which innumerable individuals have to live, the affordability of free HAART and other forms of health care need to be taken into careful account within the context of the whole health care equation because these factors can undermine the success of any free HAART programme, however well designed it may be. Individual poverty in Africa (as well as in other regions of the world) is a factor that needs to be taken into consideration when policymakers and health care experts design free ART and other patient treatment programmes.

Finally, well-informed advocacy for universal access to ART is important if the current mortality rates are to be contained and reduced to levels far below those that are currently observable in sub-Saharan Africa.

5.8 FURTHER RESEARCH

The researcher identified the following key themes, topics and problems for further research.

What is the gender distribution of adult mortality for the deaths that occur in the community (i.e. for those deaths that are not reported in formal health system records)? In other words, are more females than males dying deaths occurring in the community?

Why do more males than females die in hospital? Is this phenomenon related to obstacles that prevent males from accessing health care services more readily? Or is it the case that more males with terminal illness are accessing health services in comparison to the number of females with terminal illness who access hospital services?

The medical records in the hospital's archives revealed that not only did males die in greater numbers than females, but that the annual increase in male deaths in the post-free ART era was 4.7 times greater than the annual increase in the number of female deaths. This is obviously a set of problems that urgently requires further research and investigation.

Apart from the cost of health services in terms of out-of-pocket payments that the researcher investigated in this study, the continuous and timely supply of the necessary ARV medicines and other possible barriers that prevented ready access to ART were beyond the scope of this study. Nevertheless, these barriers represent important factors in the chain of HAART delivery, and can result in major challenges to effective service delivery to those who most need it in an.

This study revealed a proportional decrease in the number of deaths in the 15-24 and 25-34 year age groups and an increase in the 35-44 and 45-54 year age groups in the post-free ART era when statistics from that era are compared to statistics from the pre-free ART era. The question that arises is: *What is happening in these specific four age groups that results in these particular trends?*

The relationship between mortality trends and ART access at the level of districts and sub-districts are areas that need further detailed research.

Although the associations between the age at time of death of various groups of patients who have been on an ART regimen of varying lengths of time was beyond the scope of this study, it is also an area that requires future research.

5.9 CONCLUSION

The researcher concluded from the literature review that HIV/AIDS has made a devastating impact on mortality trends throughout the world but especially in sub-Saharan Africa. While the introduction of ART into developing countries has reduced the mortality that is attributable to HIV-related causes, some studies that were undertaken in developing countries had indicated that mortality rates have diminished in proportion to the greater availability of access to free ART.

Since Uganda has been providing free ART to the public for over four years in all of the district hospitals and health centres in the country, it has been able to point to some remarkable achievements in the fight against HIV/AIDS. The theoretical expectation in Uganda (where free antiretroviral therapy has been available to HIV-infected patients for the past four years) was that clear positive or negative mortality trends would reveal themselves to investigators. It was on the basis of this assumption that this study was undertaken to determine the effects of free access to antiretroviral therapy on mortality rates in a rural hospital. The researcher therefore undertook this study in Mpigi district – a rural district in Uganda that has borne a significant burden of HIV morbidity and mortality rates during the past decade. Mpigi district is one of the rural districts in Uganda that has satisfactorily met the targeted objectives of this study. On the basis of the literature review that he conducted, the researcher explored mortality trends by means of this study in a rural hospital setting with a view to making recommendations about facilitating and expanding access to ART for those patients who needed it.

But the findings of this study revealed that the hypothesis that states that *the introduction of free antiretroviral treatment in a rural hospital lead to a reduction in the overall morbidity and mortality* was not entirely true of Mpigi District. In Mpigi District hospital, the number of admissions diminished and did indeed reveal a downward trend,

but the hospital mortality rate increased and demonstrated a clear upward trend. The researcher therefore concluded that after three years of free access to ART in Mawokota South health sub-district, the hospital mortality had increased and had revealed an increasing trend. The number of deaths from two of the sub-counties (Nkozi and Buwama), each of which had a designated ART site reduced with increasing availability of free ART.

While an increased access to ART at the sub-county level did indeed contribute to a reduction in mortality from the sub-counties who enjoyed ready access to ART, this but did not lead to an overall reduction in the mortality rates in the district hospital.

This study has emphatically emphasised the urgent need for a careful, meticulous and regular monitoring of the mortality and morbidity rates of highly prevalent diseases such as HIV/AIDS in public health interventions – a recommendation that has also been emphasised by officials and researchers from the WHO on many different occasions. Mortality trends are important because they guide the design and implementation of ART programmes at the district and national levels, and it is vitally important to determine whether the goals of free access to ART are being adequately accomplished.

This study investigated and identified the morbidity and mortality trends in a rural hospital setting and identified a variety of factors that were associated with hospital mortality. The study also identified the research and information gaps that need to be investigated so that an adequate amount of information can be made available for evidence-based decision-making. Such findings as these will be able to serve as benchmarks for evaluating mortality trends and will provide a solid basis of research-based investigations that will be able to guide future studies into the problem of hospital mortality research rates as all who are concerned with public health and well-being attempt to design and implement interventions that will reduce the current rates of patient mortality.

The findings in this study will therefore serve as a benchmark for future research activities as researchers and those concerned with macro health policy develop interventions to reduce current rates of mortality and meet the targets of the Uganda National Strategic Plan for HIV/AIDS. Targeted interventions will enable Uganda to attain goal number six of the Millennium Development Goals that targets combating

HIV/AIDS, malaria and other diseases and focuses on ensuring that by 2015, throughout the world, the spread of HIV/AIDS should have been halted or reversing (UN 2008:28).

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